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HEALTH TECHNOLOGY CASE STUDY 26:

Assistive Devices for Severe Speech Impairments

DECEMBER 1983

This case study was performed as a part of OTA's Assessment of

Technology and Handicapped People

Prepared for OTA by:

Judith Randal, Congressional Fellow
Office of Technology Assessment, U.S. Congress

OTA Case Studies are documents containing information on a specific medical technology or area of application that supplements formal OTA assessments. The material is not normally of as immediate policy interest as that in an OTA Report, nor does it present options for Congress to consider.

CONGRESS OF THE UNITED STATES
Office of Technology Assessment
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Preface

Assistive Devices for Severe Speech Impairments is Case Study 26 in OTA's Health Technology Case Study Series. It is part of OTA's project on *Technology and Handicapped People*, requested by the Senate Committee on Labor and Human Resources. A listing of other case studies in the series is included at the end of this preface.

OTA case studies are designed to fulfill two functions. The primary purpose is to provide OTA with specific information that can be used in forming general conclusions regarding broader policy issues. The first 19 cases in the Health Technology Case Study Series, for example, were conducted in conjunction with OTA's overall project on *The Implications of Cost-Effectiveness Analysis of Medical Technology*. By examining the 19 cases as a group and looking for common problems or strengths in the techniques of cost-effectiveness or cost-benefit analysis, OTA was able to better analyze the potential contribution that those techniques might make to the management of medical technology and health care costs and quality.

The second function of the case studies is to provide useful information on the specific technologies covered. The design and the funding levels of most of the case studies are such that they should be read primarily in the context of the associated overall OTA projects. Nevertheless, in many instances, the case studies do represent extensive reviews of the literature on the efficacy, safety, and costs of the specific technologies and as such can stand on their own as a useful contribution to the field.

Case studies are prepared in some instances because they have been specifically requested by congressional committees and in others because they have been selected through an extensive review process involving OTA staff and consultations with the congressional staffs, advisory panel to the associated overall project, the Health Program Advisory Committee, and other experts in various fields. Selection criteria were developed to ensure that case studies provide the following:

- examples of types of technologies by function (preventive, diagnostic, therapeutic, and rehabilitative);
- examples of types of technologies by physical nature (drugs, devices, and procedures);
- examples of technologies in different stages of development and diffusion (new, emerging, and established);
- examples from different areas of medicine (e.g., general medical practice, pediatrics, radiology, and surgery);
- examples addressing medical problems that are important because of their high frequency or significant impacts (e.g., cost);
- examples of technologies with associated high costs either because of high volume (for low-cost technologies) or high individual costs;
- examples that could provide information material relating to the broader policy and methodological issues being examined in the particular overall project; and
- examples with sufficient scientific literature.

Case studies are either prepared by OTA staff, commissioned by OTA and performed under contract by experts (generally in academia), or written by OTA staff on the basis of contractors' papers.

OTA subjects each case study to an extensive review process. Initial drafts of cases are reviewed by OTA staff and by members of the advisory panel to the associated project. For commissioned cases, comments are provided to authors, along with OTA's suggestions for revisions. Subsequent drafts are sent by OTA to numerous experts for review and comment. Each case is seen by at least 30 reviewers, and sometimes by 80 or more outside reviewers. These individuals may be from relevant Government agencies, professional societies, consumer and public interest groups, medical practice, and academic medicine. Academicians such as economists, sociologists, decision analysts, biologists, and so forth, as appropriate, also review the cases.

Although cases are not statements of official OTA position, the review process is designed to

satisfy OTA's concern of each case study's scientific quality and objectivity. During the various stages of the review and revision process, therefore, OTA encourages, and to the extent possible requires, authors to present balanced information and recognize divergent points of view.

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[b]Original publication numbers appear in parentheses.

[c]The first 17 cases in the series were 17 separately issued cases in *Background Paper #2: Case Studies of Medical Technologies*, prepared in conjunction with OTA's August 1980 report *The Implications of Cost-Effectiveness Analysis of Medical Technology*.

[d]Background Paper #3 to *The Implications of Cost-Effectiveness Analysis of Medical Technology*.

[e]Background Paper #5 to *The Implications of Cost-Effectiveness Analysis of Medical Technology*.

[f]Background Paper #1 to OTA's May 1982 report *Technology and Handicapped People*.

[g]Background Paper #2 to *Technology and Handicapped People*.

OTA Staff for Case Study #26

H. David Banta, *Assistant Director, OTA*
*Health and Life Sciences Division**

Clyde J. Behney, *Health Program Manager*

Clyde J. Behney, *Project Director*

Anne Kesselman Burns, *Analyst*

Kerry Britten Kemp, *Editor*

Ann Covalt, *Contractor*

Virginia Cwalina, *Administrative Assistant*

Mary E. Harvey, *Secretary*

Jennifer Nelson, *Secretary*

OTA Publishing Staff

John C. Holmes, *Publishing Officer*

John Bergling Kathie S. Boss Debra M. Datcher Joe Henson

Glenda Lawing Linda A. Leahy Cheryl J. Manning

*Until August 1983.

Advisory Panel on Technology and Handicapped People

Daisy Tagliacozzo, *Panel Chair*
Department of Sociology, University of Massachusetts, Harbor Campus

Miriam K. Bazelon
Washington, D.C.

Tom Beauchamp
Kennedy Institute—Center for Bioethics
Georgetown University

Monroe Berkowitz
Bureau of Economic Research
Rutgers University

Henrik Blum
University of California, Berkeley

Frank Bowe
Woodmere, N.Y.

Jim Gallagher
Martha Porter Graham Center
University of North Carolina, Chapel Hill

Melvin Glasser
Committee for National Health Insurance

Ralf Hotchkiss
Oakland, Calif.

John Kimberly
The Wharton School
University of Pennsylvania

Robert Leopold
Department of Psychiatry
Hospital of the University of Pennsylvania

LeRoy Levitt
Mount Sinai Hospital

A. Malachi Mixon, III
Invacare Corp.

Jacquelin Perry
Rancho Los Amigos Hospital

Barbara W. Sklar
Mount Zion Hospital

William Stason
Veterans Administration and Harvard School of Public Health

Gregg Vanderheiden
Trace Research and Development Center
University of Wisconsin-Madison

Michael Zullo
Corporate Partnership Program
U.S. Council for International Year of Disabled Persons

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David Beukelman
Director, Speech Pathology
University of Washington
Medical Center
Seattle, Wash.

Colette Coleman
Professor of Speech Pathology
California State University
Sacramento, Calif.

Yvonne Danjuma
Graduate Assistant
Office of Programs for Handicapped Students
Michigan State University
East Lansing, Mich.

Charles Diggs
Director, Speech-Language Pathology Liaison Branch
American Speech-Language-Hearing Association
Rockville, Md.

Allen T. Dittmann
Chief, Research Projects Section
Special Education Programs
U.S. Department of Education
Washington, D.C.

John Eulenberg
Associate Professor of Computer Science
Audiology and Speech Sciences and Linguistics
Artificial Language Laboratory
Computer Science Department
Michigan State University
East Lansing, Mich.

Alexandra Enders O.T.R.
Coordinator Information Dissemination
Rehabilitation Engineering Center
Children's Hospital at Stanford
Palo Alto, Calif.

Cheri Florance
Department of Speech Therapy
St. Anthony's Hospital
Columbus, Ohio

Richard Foulds
Director
Rehabilitation Engineering Center
Tufts University
Boston, Mass.

Carol Galaty
Director, CHAMPUS Liaison Office
Department of Defense
Washington, D.C.

Bruce Gans
Chairman, Department of Rehabilitation Medicine
New England Medical Center
Boston, Mass.

E. Paul Goldenberg
Waban, Mass.

Anna Hofmann
Market Researcher
Phonic Ear, Inc.
Mill Valley, Calif.

Mr. and Mrs. Richard Hoyt
Westfield, Mass.

Arlene Kraat
Speech and Hearing Center
Queens College
Flushing, N.Y.

Maurice LeBlanc
Director of Research
Rehabilitation Engineering Center
Children's Hospital at Stanford
Palo Alto, Calif.

Christy Ludlow
Director
Division of Communication Disorders
National Institute of Neurological and Communicative
Disorders and Stroke
National Institutes of Health
Bethesda, Md.

Nola Marriner
Department of Speech and Hearing
University of Washington
Seattle, Wash.

Judith McDonald
Department of Speech and Hearing
University of Washington
Seattle, Wash.

Shirley McNaughton
Director
Blissymbolics Institute
Toronto, Canada

Laura F. Meyers
Speech Communication Research Laboratory
University of California
Los Angeles, Calif.

Judy Montgomery
Director, Non-Oral Communications for Fountain Valley
School District
Fountain Valley, Calif.

Rochelle Moss
Director
National ALS Foundation
New York, N.Y.

Robert Munzer
Chief Neurological Devices Branch
Division of Anesthesiology and Neurology Devices
Food and Drug Administration
Rockville, Md.

Carol Nugent
Director, Speech and Language Pathology
Good Samaritan Hospital
Portland, Oreg.

Ralph Naunton
Director, Communicative Disorders Program
National Institute of Neurological and Communicative Disorders and Stroke
National Institutes of Health
Bethesda, Md.

Gail Pickering
Speech Pathologist
Northridge Hospital Medical Center
Northridge, Calif.

Barry Romich
President
Prentke-Romich Co.
Shreve, Ohio

Lawrence Scadden
Arlington, Va.

Pamela Schiffmacher
Director, Speech Pathology
Northridge Hospital Medical Center
Northridge, Calif.

Howard S. Shane
Director, Communication Enhancement
The Children's Hospital
Boston, Mass.

Robert J. Slater
Director, Medical and Community Services Department
National Multiple Sclerosis Society
New York, N.Y.

Barbara C. Sonies
Speech Pathologist
Clinical Center
National Institutes of Health
Bethesda, Md.

Leon S. Sternfeld
Medical Director
United Cerebral Palsy Association
New York, N.Y.

Christine Thompson
Trace Research and Development Center for the Severely Communicatively Handicapped
University of Wisconsin
Madison, Wis.

Gregg C. Vanderheiden
Director, Trace Research and Development Center for the Severely Communicatively Handicapped
University of Wisconsin
Madison, Wis.

Larry Weiss
President
Zygo Industries
Portland, Oreg.

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OTA Note

These case studies are authored works commissioned by OTA. Each author is responsible for the conclusions of specific case studies. These cases are not statements of official OTA position. OTA does not make recommendations or endorse particular technologies. During the various stages of review and revision, therefore, OTA encouraged the authors to present balanced information and to recognize divergent points of view. Since the research and writing of this case study in 1981 and 1982, there have been significant technological changes that may not be adequately represented in this study.

1.
Introduction

1. Introduction

Lack of speech is a serious disability. When combined with other disabilities that render a person functionally unable to write or type, it is more serious still. Whatever their age and whether or not they are of normal intelligence, people with such disabilities are very likely to be placed in institutional care. And if they are people who—because of a genetic defect, an accident during gestation or an injury at birth—have never talked, chances are they will be assumed to be profoundly mentally retarded and so will also have been deprived of that education without which no one in this society can aspire to enter the work force or to live as an independent adult.

Children whose speech is limited or are mute because of congenital deafness, but who can use their arms and hands, have long had the opportunity to learn sign language, usually learn to read, write, and spell with some proficiency, and often learn to speak as well. By contrast, children with the kinds of central nervous system damage that preclude both the development of speech and the development of hand and finger motor skills have traditionally not been taught a systematic means—oral, written, or gestural—to communicate either with each other or with the outside world.

People of all levels of intelligence are found in the population with the inability to speak which is one of several neurological or neuromuscular impairments. But, only rarely have distinctions been drawn between those incapable of thinking of comprehending and those who simply cannot express themselves. Lack of speech has been confused with lack of language and often been automatically equated with lack of intelligence.

As recently as the mid-1970's, there was little or no remedy for either the congenital or the acquired inability to speak when accompanied by severe physical disability. Affected individuals could often communicate with those in their immediate circles by resorting to eye signals, other forms of private language, or the use of primitive language boards. But the emotional and intellectual content of such interactions was limited, consigning these people to social isolation, passivity, and custodial care.

This case study is about the revolution in communication aids that has since changed the outlook for this population, its accomplishments to date, its promise for the future, and its problems. It is also about related public policy and the barriers to fully utilizing the technology now available for the benefit of the individuals in question, their friends and families and society as a whole.

As no ability is more highly valued in complex modern societies than the ability to exchange and process information, this study deals with a disability that is like no other. But, insofar as people with many handicapping conditions are faced with a poor fit between their potential and the means available to them to fulfill it, this case study is applicable to virtually the entire disabled community.

TERMINOLOGY

The nonspeaking population is referred to by a variety of terms, including severely speech-impaired, speechless, nonoral, nonverbal, and others. The reason for the multiplicity of terms is that some of the individuals in question can actually produce sounds or a limited amount of speech, but nonetheless qualify as nonspeaking because what they say is unintelligible, inaudible, or both.

A position paper developed by an ad hoc committee of the American Speech-Language-Hearing Association in January 1980 and revised in 1981 defined a nonspeaking person as one for whom

"speech is temporarily or permanently inadequate to meet all of his or her communications needs and whose inability to speak is not due primarily to a hearing impairment" (35). With the proviso that stuttering and the lack of speech associated with autism will be excluded from consideration—because these disorders are not seriously physically disabling—that definition is the one that will be used here.

The case study will also touch very little on aphasia, language disorder following brain injury, and the anomia that often accompanies it, which are less the inability to speak than the inability to find the right words to articulate an idea. While this last qualification excludes from consideration many people who have had cerebrovascular accidents (strokes), it does not exclude those—many of them children—who have had the kind of stroke that injures the brain stem and does not result in aphasia.

DEMOGRAPHY

No precise count is available of nonspeaking persons in the United States who meet the above description. Nor has any census been taken of how many nonspeaking persons owe their difficulties only to developmental problems—inherent difficulty in reading or producing meaningful speech, despite intelligence in the normal range—and how many are also mentally retarded, or mentally retarded alone. It can be said, however, that: 1) more males than females are found in the nonspeaking population, and 2) statistical inferences point to there being at least 750,000 to 1.5 million severely disabled nonspeaking children and adults in this country. Included in this estimate are approximately 90,000 people with congenital impairments (primarily but not entirely a consequence of cerebral palsy); 500,000 with acquired disabilities resulting from severe illness or fever, head trauma, or stroke; and 140,000 persons who have progressive disorders of the central nervous system such as amyotrophic lateral sclerosis (abbreviated as ALS, and known as motor neuron disease in Britain and popularly as Lou Gehrig disease in the United States), multiple sclerosis, dystonia musculorum deformans, some forms of muscular dystrophy, Parkinson's disease, myasthenia gravis, Huntington's chorea, Friedreich's ataxia, and ataxia telangiectasia (9).

It is difficult to estimate the incidence and prevalence of severe speech impairment, because this functional disability affects some, but not all, people in given diagnostic categories, and the numbers of people counted in those categories are often themselves only estimates.

For example, speech loss is frequently an early sign of the bulbar form of ALS and occurs, as well, in other forms of this lethal disease. But the National ALS Foundation does not know how many people there are in the United States with ALS, nor how many of them are unable to talk (30).

Similarly, the United Cerebral Palsy (CP) Association can only make an educated guess that there are 750,000 individuals with CP in the United States, that 85 to 90 percent of them are speech-impaired, and of that 85 to 90 percent, about 30 percent are without any useful speech (46). The incidence of CP is estimated to be 25 per 10,000 live births. This means that, of those 25, approximately 7 will probably never be able to talk.

Much the same is true of those with chronic degenerative nervous system disorders. Parkinson's disease (popularly known as shaking palsy) is a case in point. First surgical intervention and then the development of specific drug therapy during the 1960's have at least temporarily spared many patients the severe motor symptoms of Parkinson's. But neither mode of treatment has achieved much, if any, improvement in the speech deterioration of these patients. Although no rigorous data are available as proof, the clinical impression of some observers is that, in some cases, the

gain in life expectancy and control of tremors may have been at the expense of accelerating speech deterioration (21).

More than 2,000 Americans each year develop Guillain-Barré Syndrome (popularly known as French polio), which became familiar to the public as a complication of the swine flu vaccine, but can also occur under other circumstances (49). About 75 percent of those with this disease experience loss of speech. Though the loss is usually temporary, it is frightening nonetheless, especially because recovery from this disease is often slow (16).

Current surgery for cancer of the head and neck often includes removal of the larynx, and less frequently, removal of the entire tongue and soft palate. All three procedures obviate the possibility of unaided speech. Again, no precise estimate of the number of persons affected is available.

The absence of reliable data on the size of the physically disabled nonspeaking population and the reasons for their disabilities is a contributing factor to the often inadequate rehabilitation and needlessly high cost of caring for this population.

2.
Case Studies

2.
Case Studies

Speech is so much second nature to most people that they cannot imagine what it would be like to be without it. The following vignettes suggest the anger, frustration, helplessness, and despair of not being able to express one's thoughts and feelings by any reliable means for years on end. They are included because they describe actual people whose lives have been changed by assistive communication technologies. OTA thanks Ms. Carol Nugent, Director of Speech and Language Pathology at the Good Samaritan Hospital in Portland, Oreg., for telling us most of these stories. With the exception of Ricky Hoyt, whose real name is used (with permission), all names and some identifying details have been changed to protect the privacy of those involved.

Joey Crandall's mother was watching TV one afternoon last spring in Portland, Oreg., when a short feature came on about the speech language pathology department at the Rehabilitation Institute of the Good Samaritan Hospital there. That one feature is why this 10-year-old, whose normal language development began and ended while he was still a toddler, is learning to communicate with others for the first time since he was old enough to go to school.

Joey has been unable to communicate because the carotids, the two major arteries that furnish blood to the head and brain, did not form properly before his birth. Because of their weakness, he was only 3 when he had a cerebrovascular accident, what is commonly called a stroke. He now walks, although he must drag one leg through with every step. He has occasional seizures, and the best he has been able to do in the way of talking is to make noisy cries. Despite the boy's having had 7 years of conventional speech therapy, even those in his family do not always know what his cries mean.

Upon Joey's arrival at Good Samaritan, one of the first objectives of the assessment team was to determine what parts of his body the child might use to link him to a system that would serve him in the place of speech. His left hand was nearly useless, so that was out. He could not hold a pencil with his right hand, even with finger splints, but the rehabilitation staff became persuaded that he could gain sufficient control of it to be able to turn a switch or buttons on and off. The result is that Joey now has a HandiVoice 110, a portable synthetic voice communication aid with a touch-sensitive keyboard.

Paid for by a local organization, the Scottish Rite Institute of Childhood Aphasia in Portland, Oreg. (1 of 25 such institutes in the United States), this device was selected for Joey because he has so long been isolated in his own private world that he needs the feedback he gets from hearing the machine respond out loud to his touching it to encourage him to emerge from his shell. Within a week or so of getting the aid he was already programing it to say things like "I want a cookie" and "Where is Mom?"

Taking the initiative is, indeed, a lot of what Joey is discovering having the HandiVoice is all about. Tommy, his 6-year-old brother, and Lisa, his 8-year-old sister, had grown accustomed to talking for Joey. With the help of the Scottish Rite Institute, they all attend therapy together so that the younger children will come to understand that, though they may explain or amplify when necessary, it is Joey who should be in charge of what he wants to say.

Joey had been in public school, but enjoying only what his speech therapist termed "a haphazard experience." Because he had never been able to actively participate in class, he had never really learned to read, write, spell, or do arithmetic.

At the private school where he was enrolled after getting his HandiVoice, Joey has the benefit of a teacher familiar with nonvocal youngsters who is willing to coordinate her program for speaking pupils with special teaching strategies for him. Though no one yet knows how much lost time he can make up for (the intelligence of people in Joey's situation is hard to test), the plan is to help him progress as rapidly as his communication system allows.

Bryan Wilson is another client of Good Samaritan. Bryan was delivering newspapers after school when he was struck by a hit-and-run driver who was later apprehended by the police and convicted. He was then just about to celebrate his 15th birthday, and, as this was written, has recently turned 18.

Bryan now needs a cane to walk, which he can do only with difficulty. The brain damage from the accident was such that his hand and finger functions are limited and he has yet to regain his speech. Nonetheless, Bryan was able to graduate with his high school class in June 1981, and, after spending the summer helping his 17-year-old brother, Sam, to paint houses (Sam would position him on the floor so he could do the trim), he entered Portland State University that fall.

Little of this would probably have been possible had Bryan been injured in 1968 instead of 1978. Bryan uses a small, portable, battery-powered tape typewriter called a Canon Communicator, which he wears suspended from his belt buckle, for informal face-to-face conversations and a second machine, called a Portatel, with a lighted display for work in class. (Bryan is fortunate that the funding of these devices was not a problem—he qualified for worker's compensation and was also covered by the liability insurance of the driver who injured him.)

At Good Samaritan's Rehabilitation Institute assistive communication is arranged not only for the young. Although the Rehabilitation Institute counts among its clients people like 16-year-old Sue Jones, whose loss of muscular control and speech 2 years ago resulted from a high fever during a bout of toxic shock syndrome, and 25-year-old Jack Brown, who was left paraplegic and severely speech-impaired by a motorcycle accident, Good Samaritan also has older speech-impaired clients.

One, Earl Higginson, now in his forties, had two strokes within 5 months—the first on the left side of his brain, the second on the right side—about 8 years ago. Complications developed after his second stroke that threatened to drown him in his own saliva, and surgeons were forced to tie off his vocal cords to prevent fluid from flooding his lungs. While this procedure is usually reversible, the damage to the cords was permanent by the time Higginson was sufficiently recovered to undergo the restorative surgery. After long months of convalescence, it was clear that he was as alert and intellectually competent as ever, but that his prospects of being able to talk again were extremely poor.

Higginson cannot use his left arm, has some residual difficulties in walking, and lost his position as an accountant soon after he became ill. Yet he is not an invalid and now rides the public bus alone to and from a new full-time job that, although not as demanding as his old one, gives him the satisfaction of again being able to support his wife and daughters and entails the considerable responsibilities of handling payroll and inventory for his employer. He has been able to assume these responsibilities by learning to use a Canon Communicator for written communication and a HandiVoice 110 for telephoning. Both devices were bought for him with vocational rehabilitation funds.

Rosalie Hathaway's case is sadder, but is included here because it represents many others.

Until 1974 when she had a massive stroke, Mrs. Hathaway lived in the San Francisco Bay area with her husband and two daughters, who were then in the third and fifth grades. Since that time she has been confined to a nursing home in a small eastern Oregon town. She was taken there to be near her mother, and because her husband thought it best for the children not to visit her.

If his decision seems callous, it should be said that, since her brain hemorrhage, Mrs. Hathaway, who was 41, when this was written, is completely paralyzed below her neck and above it has constant tremors. In addition, her vision is poor, and she has severe difficulties in swallowing. Her meals must be pureed and spoon-fed to her and, nonetheless, take her 40 minutes to consume. Even that is a triumph. Before an arduous swallowing retraining program, she had to be fed by stomach tube.

Mrs. Hathaway, however, is by no means completely debilitated. Though the only sounds she can make are squawks, her mental faculties are intact, and she can still read and spell. Apart from

a large screen television that she can watch both from her bed and a wheelchair, her greatest material joy is a portable device called a Zygo 100. It has an electronic memory that allows her to compose whatever she wants to say, a message display large enough for her to see, and a buzzer so that she can summon attention when she is ready to have the text read.

How does a woman who cannot so much as feed herself operate a machine? That was not an easy problem for the rehabilitation team at Good Samaritan to solve. They found that there was only one muscle, in her chin, over which she had some control. Using this muscle to control the Zygo's switches, Mrs. Hathaway is able to guide the device's indicator to the items she selects on the electronic communications board, and has made truly remarkable progress. Whereas it took her about 20 minutes to compose a sentence a year ago, it now takes her about 3, and she is still gaining speed as ways are found to better adapt the system to her needs.

Mrs. Hathaway's ability to express herself again has reduced the time her nurses must spend in caring for her by about a third. She can now alert them to impending bladder infections, threatened bedsores, and other problems before they become acute.

But most of all, her communication system has enabled her to share everything from her fantasies and her reactions to what she sees on television to what she wants to have her mother tell her daughters when she writes to them on her behalf. Hathaway is the first to say that this system has enhanced the quality of her life.

RICKY HOYT'S STORY

When their first child was born in 1962, it wasn't obvious to the Hoyts that anything was wrong. But Ricky didn't develop as most babies do, and within a year the Hoyts—who live in Westfield, Mass.—were to learn of a disorder they had never heard of. Pediatricians told them that Ricky had a very serious case of cerebral palsy. He would never walk or be able to feed himself and was mentally retarded. "Put him in an institution," the pediatricians advised the Hoyts, "he will always be a vegetable."

Two decades later, it is true, as predicted, that Ricky cannot walk or feed himself. The Hoyts felt intuitively, however, that their son was bright. So when their minister told them they had a choice between really going to bat for him or feeling sorry for themselves forever, they decided to seek out the best professional help available.

Because the Hoyts live in Massachusetts, they took the child to the cerebral palsy unit at Children's Hospital in Boston soon after they were told of his prognosis. There, he was seen periodically by a team of rehabilitation experts, and Judy Hoyt, his mother, was instructed in how to provide the little boy with daily therapy sessions at home.

"In those days," she recalls, "a technique called 'brushing and icing' was part of the standard treatment for cerebral palsy kids like Ricky," who, in addition to their other problems, were seriously speech-impaired. The idea was that cracked ice regularly applied to their mouths and throats with a toothbrush would reduce the flaccidity of the speech-producing muscles and eventually enable these children to talk.

"Ricky and I did all his physical therapy sessions together and enjoyed most of them, but both of us hated this," she recalls. "Besides, it became very evident that we weren't getting anywhere. Ricky was 7 or 8 when the speech therapist at Children's finally had the guts to say 'Hey, this child is really never going to speak and we need to be looking for other ways for him to communicate.' To hear him say it, at last, came as a relief."

Meanwhile, Ricky had long since begun to do such things as look at the refrigerator when he was hungry or thirsty, or at the window when he wanted to go out. So Judy, more confident than ever that the child was not stupid, had already begun her own program to give Ricky a foundation for language skills.

A psychologist at Children's Hospital in Boston had suggested to her that, since Ricky couldn't even crawl, she bring the material world to him by rubbing his body with a variety of objects—some hard, some soft, some smooth, some rough—so that he could explore these sensory realities for himself. Eventually, she hit on cutting letters out of sandpaper to enable him to learn the alphabet and begin to learn to spell. As it happened, the psychologist was a wheelchair user. This further convinced the Hoyts that handicapped people could succeed. And it was a bonus that they drew the courage from their counseling sessions with him to have another baby. Their second son Robby, was born to the couple when Ricky was 2 and a third son, Russell, when Ricky was 6.

But, the arrival of Russell is getting ahead of the story. It is characteristic of Judy that, when Ricky was 4, she arranged to enroll him in a church-sponsored nursery school and kindergarten in exchange for her caring for the teachers' children and the children of several women who agreed to fulfill his special needs of toileting, feeding, and play during the hours he was away from home.

Judy also taught her disabled son to swim (and has since taught other disabled youngsters to swim as well). The head control Ricky gained in the process is probably largely responsible for his being able to operate both the switches that control his electric wheelchair and those for what the Hoyts call "the hope machine."

The "hope machine" is more formally known as the Tufts Interactive Communicator—the TIC for short. This machine, developed at Tufts University, uses a lighted letter display board and paper strip printer to enable nonvocal people, otherwise incapable of writing, to communicate. Had it not been for Ricky, this device might not exist.

In addition to being seen by therapists at the Children's Hospital in Boston, Ricky was also regularly seen by an occupational therapist at a cerebral palsy clinic closer to his home. One day, Judy went to a conference there, where she met Richard Foulds, then a graduate student in rehabilitation engineering at Tufts. Foulds has been toying with building a communication system for severely physically handicapped nonvocal people, and once the occupational therapist introduced him to Ricky, he agreed to try to make the concept a reality.

First, however, there was a major obstacle to overcome. The parts to build prototypes and a production model would cost about $5,000, and at that point neither Foulds nor his university had the funds. Through a dinner dance their church sponsored and a series of bake sales, yard sales, and other activities, the Hoyts and their neighbors raised the money. Foulds began to design the machine in earnest when Ricky was 8. When Ricky was 10, the first TIC ever made for practical use became his for keeps.

The Hoyts were, of course, elated. Only one hurdle remained: except for a special education program described by Judy as "not very systematic," they had never been able to get Ricky into public school. They had succeeded in pressuring the authorities to move the special education program from space in an old age hospital into the back room of an actual school. But every time they attempted to have Ricky go to classes with able-bodied youngsters of normal intelligence, school officials adamantly refused.

Still undaunted, the Hoyts resorted to a kind of "back door" approach. They hired tutors, among them some youngsters who were proficient at science and arithmetic. These children came to like Ricky and to realize that he was as capable of learning as they were. "He doesn't need to be in a special class," they told their teachers. And so even before Ricky was 12—when the law in Massachusetts changed to make "mainstreaming" his right and he was admitted to fifth grade—he was allowed to attend regular classes in science and arithmetic. With the change in the law and Ricky's TIC, the schools could also no longer believe that his parents might be answering for him when he was tested. The answers Ricky programed the device to produce were unmistakably his own.

Ricky is 21 now. He graduated from high school with the class of 1983, is taking two courses at Westfield State College in Westfield, Mass., and has been admitted to Boston University. He plans a major in computer programing and will enter

the University in January 1984. Meanwhile, he has been supplied with new communication equipment, designed and assembled by Richard Foulds and his colleagues at Tufts University, largely from Radio Shack components, which has both synthetic voice and print-out capabilities.

3.
Assistive Communication Systems

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Assistive Communication Systems

CLASSIFICATION OF ASSISTIVE COMMUNICATION SYSTEMS

Communication systems for the nonspeaking may be unaided or aided by manmade devices. Unaided systems are often also described as manual, gestural, or supplementary. While they have the advantage of needing no external materials, they are of little use to persons whose arms and head are paralyzed or who cannot control their movements. Some of these people can blink their eyes to signify yes or no, and become quite adept at conveying meaning by systematically changing their direction of gaze and focus. But this hardly constitutes more than marginal communication unless the receiver knows the sender's signals and can interpret them. For those who use sign language, face-to-face encounters with persons also familiar with sign language are required. And, as is true of virtually all unaided systems, sign language cannot be transmitted either in writing or by most telephones.

Aided systems range from simple language symbol or alphabet boards without any mechanical or electrical parts that may be made or purchased for only a few dollars, to electronic devices—some computerized—that may have price tags of $5,000 to $6,000 or more. Whether simple and inexpensive, or costly and complex, or somewhere in between, all aided communication systems require the user to tell the equipment what to say. This is accomplished in one of three ways.

The first is direct selection. An ordinary mechanical or electric typewriter is a typical direct selection device, but one ill-suited to the many people with severe speech disabilities secondary to severe disabilities. Accordingly, direct selection communication aids for this population may have keyboards that require less manual dexterity than the ordinary typewriter keyboard, or may have matrix displays on their surfaces of pictures, symbols, letters, groups of letters, or phrases, or some combination of these, that the user points to or presses on as the information he or she wishes to convey.

Although direct selection devices are far from as rapid as normal speech and so are somewhat frustrating to even the most adept users (the more so because speaking persons are often too impatient to let users complete their thoughts), they are still intrinsically the fastest way for nonspeaking perons to communicate. Some electronic direct-selection devices have computerized memories that make it possible to compose a fairly lengthy message in advance and a printing capability that releases this product from storage on the user's command. Others make a modicum of informal "conversation" possible by printing short messages while the listener is present, or by displaying such messages on small screens in light-emitting diode or liquid crystal display lettering. Some machines have both print and display capabilities.

Because of their physical limitations, however, many nonspeaking persons cannot transmit their thoughts to others by direct selection. Even if they are supplied with an input link to the device (often called an interface), such as a foot or tongue operated switch, a breath-operated sip-and-puff switch, a joy-stick, or a wand or optical light pointer (worn on a band or straps around the head), they simply do not have sufficiently fine-tuned motor control. For these individuals, electronic scanning devices that make the selection on the user's behalf are often more appropriate. With these devices, the user scans a "menu" of possible choices and selects one by means of a simple yes-or-no response. Some of these scanning devices can also be used in direct selection mode.

Scanning communication devices differ in detail, but all of them present the user with: 1) components of vocabulary—i.e., numbers, letters, groups of letters, words, phrases, pictures, symbols, etc., or some combination of these; and 2) an indicator mechanism on the display that serves as a pointer. With an input attachment for this kind of selection (and sometimes without one,

for example, if the person can use his elbow or balled fist for input), nonspeaking persons can have these communication aids sweep the field until the desired place on the display is reached and then simply instruct the pointer or indicator to come to a stop. Again, this makes person-to-person interactions possible. Some of these devices also either have printing capabilities or can be connected, for an additional investment, to separate hard copy printers.

A third form of personal communication aids are those that operate by encoding. That is, their inputs go into the unit in the form of numbers, for example, and these are then electronically converted into written or synthetic speech outputs. As a general rule, encoded systems offer the user larger vocabularies and more flexibility than direct selection on scanning units and more speed than scanning units. Their disadvantages are that: 1) some are not portable though this may change as newer models employ miniaturized computer components, and 2) it generally takes longer to learn to use these units proficiently and requires a considerable amount of cognitive ability. For example, encoded systems may entail activating two switches simultaneously or several switches sequentially, making their operation somewhat complex.

Still, an encoding system is probably preferable to either direct selection or scanning because of its speed and versatility, providing the user is sufficiently motivated, intelligent, and cognitively intact. Professor Wesley R. Wilson and his colleagues at the University of Washington's Child Development and Mental Retardation Center developed one prototype encoding system for severely physically disabled clients of normal intelligence who can spell at least at a grade 4 level. The basis of this system is Morse code (23,25). Properly selected subjects—most of them cerebral palsied children—have been able to learn it with 80 to 90 percent or better accuracy within a month. The inherent drawback of the code—that both sender and receiver must know it—is overcome by a microprocessor that converts the dots and dashes into printed letters. The system can also be supplied with an attachment for synthetic voice output.

The core of this Morse code communication system is a computer mounted on the base of the client's wheelchair that is linked to two head switches, one to signal dots and the other to signal dashes. The switches activate a second communicator unit fitted to the front of the wheelchair (it swings out of the way when the user wishes to move from the chair) that has a liquid crystal display screen—visible on one side to the user and on the other to his listener—and a small printer for hard copy. Other capabilities of the system include an emergency call system, environmental controls, an optional synthetic voice output, and an interface for Apple computers. When programed with special software, Apple computers can increase the speed of communication by permitting the computer mounted to the wheelchair to guess, with some accuracy, words that the user has started to spell. (The user can cancel the message if the computer's guess is incorrect.) The entire system is powered by rechargeable battery. Once the user is in the chair and someone turns the system on, all the system's features are at the user's command.

Communication systems for people who are nonspeaking and severely physically disabled have been discussed thus far with regard to whether the systems are aided or unaided. They can also be considered from another perspective: as designed from the outset for a disabled population or as designed primarily for able-bodied users but usable, if modified, for the nonspeaking neurologically or neuromuscularly impaired.

There are probably well over a hundred systems of the first type, many of them one-of-a-kind models made in home workshops for a family member or friend. But no more than 40 to 50 of them have been marketed, and their sales volumes have been small, numbering at most in hundreds of units per year. (This will be discussed further in ch. 4.)

Systems designed primarily for able-bodied users include some battery-powered devices that can be used by nonspeaking disabled people without modification, providing they have sufficient manual dexterity and muscular control to operate them: the Texas Instruments Corp.'s synthetic educational aid, "Speak and Spell" (which has a

retail price of about $60), and its learning aid, the "Language Tutor" (which has the same synthetic voice component and sells for about $150) have been employed by some of the nonvocal both for face-to-face conversations and to convey information over the telephone—though their use for the second purpose is cumbersome.

The more recently introduced Sharp Electronics Co. Memowriter, widely advertised to executives in airline flight magazines, appears to serve the same purposes as the Canon Communicator discussed earlier: both are portable keyboard devices that print short texts on a narrow roll of paper tape. The Sharp product, at $130, costs less than a third of the $594 Canon, is smaller and lighter, and—with its calculator functions and 40 shortage keys for phrases—is more versatile and sophisticated electronically. But the Canon Communicator, unlike the Sharp instrument, is available from the manufacturer with keyboards for the motor-impaired or with a pencil-like headstick for those who cannot use their fingers at all. However, an augmented keyboard for the Memowriter is made in Canada.

Two other developments may open even greater avenues of communication for those who can neither speak nor write by normal means.

One rather recent development is the design of products for the handicapped that can be mass produced but readily customized by the manufacturer for any given user. Such products represent a middle ground insofar as they are intended for a market that is smaller than that composed of able-bodied people but larger than that composed only of severely physically disabled persons who cannot speak. Thus, these products have some potential commercial advantage.

The AbilityPhone terminal, made by Basic Telecommunications in Fort Collins, Colo., exemplifies this design trend. The purpose of the unit is to permit a severely disabled user to receive and transmit information by telephone with much the same freedom of an able-bodied caller and to further the disabled user's independence by providing an electronic reminder, a calculator, and a dial-for-help capability. Relying on microprocessors, the unit can also turn on or off as many as 15 lights and appliances.

The unit's versatility lies in the compatibility of its core with an extensive selection of accessories. The unit can be ordered with precisely the options a client needs. These options include a braille keyboard, a synthetic voice output, and a variety of types of operating switches, microphones, and handsets among others. The base price of the unit which became commercially available in September 1981, is $2,335; the total cost of the system, depending on the accessories selected after client evaluation, can run as high as $3,300.

The second important development is the design of products primarily for an able-bodied person that can also be used by severely handicapped persons with a variety of disabilities. Unlike the core unit of the AbilityPhone which is designed primarily for handicapped persons, the core unit of these products is designed primarily for the far larger market of able-bodied consumers.

The preeminent example of such a system is the relatively inexpensive personal computer (retailing at about $2,000 or less), such as those marketed by Apple and Radio Shack. With relatively simple modifications, these microprocessors can be made not only the basis of communication systems for the multiply handicapped nonvocal, but can also operate environmental controls (e.g., light switches, appliances, radios, television sets, and electronic door openers). If the price of personal computers continues to drop as expected, it should become possible to provide these users many capabilities and for a fraction of the cost it now takes to provide them separately. Both Apple and Radio Shack computers have good reputations for reliability and local repair service. But, as this was written, Apple machines had the edge because workers in the handicapped field found their electronics easier to modify.

As microcomputers have become mass market items, they have attracted the attention of computer hobbyists as well as rehabilitation professionals. These amateurs can be enlisted to adapt commercially available educational and recreational software programs for the needs of disabled individuals, to write programs for the disabled population from scratch, and to write programs that speech and other professionals can use for testing.

This use of small computers may provide a psychologically healthy aura of normalcy and sophistication to physically disabled nonvocal individuals and suggest to them that computer operation and computer programing are potential sources of employment. It may also facilitate their academic work. The Maplewood Apple II Computer Project, which began in 1978, demonstrates the last benefit well (25).

Maplewood is a special education facility for moderately to profoundly handicapped children that serves 36 elementary and junior high schools in the Edmonds School District, just north of Seattle. Some of its clients attend regular classes at regular schools and go to Maplewood only for support services (Group A). Other clients attend classes in regular schools, but in classrooms set aside for the handicapped, and go to Maplewood for support services (Group B). Still others are sufficiently physically and mentally disabled that they go both to school and get their support services at Maplewood (Group C).

Nonvocal children are found in all three groups. Such children in Group C—of mental age 12 to 24 months and thus, severely cognitively impaired, are being motivated by motor-training computer games. Their counterparts in the other two groups were exposed to the Apple II through computer games and then, having gained adequate mastery of the essential operative techniques, have since used it for academic work as well. Though the degree of sophistication with which each group could use computers varied, computers have clearly helped all three of them come closer to achieving their maximum potentials.

The progress of the Group A students has been particularly dramatic. One of the children was delayed by his severe physical limitations in controlling the computer, an obstacle that has only recently been overcome. But the other three children—in grades three to eight—have made substantial gains in reading, spelling, and arithmetic and have progressed to the point where they can use commercially available educational software programs instead of individually tailored ones. Since relatively few educational software programs are marketed for children of preschool or early elementary school levels and all three of these youngsters are now beyond those points, this is a special boon. When one of the Group B boys had the opportunity to use one of Maplewood's Apple II Computers at home during the summer, he fairly quickly became able to use commercially available educational software programs, too.

In the interest of the best possible fit between client and communication systems, the assessment begins with determining the strength, as well as the disabilities, of the prospective user. The composition of assessment teams varies, but may include—in addition to the client—professionals from the following disciplines: speech-language pathology, audiology, linguistics, psychology, physical therapy, occupational therapy, rehabilitation engineering, social work, and education. (Note: the terms speech-language pathologist and speech therapist are interchangeable, but the former term is preferred.) The American Speech-Language-Hearing Association's official position on assessment for the severely physically disabled nonvocal population is:

> The central role in initiating and coordinating the services of this team should be taken by the person most likely to initiate the recommendation for an augmentative communication system, based on his/her evaluation of the client's oral motor performance, language competence, and communication needs: Further, the person needs to possess the knowledge of language development and communication interaction which will be essential to the client's success in augmentative communication. In most cases the speech-language pathologist would be the person who best meets these requirements.

One goal is to provide an interface device (between the person and the communication device) that requires the least effort and provides maximum reliability. A movement that is too difficult or tiring will cause frustration by being needlessly slow or inaccurate, and the extended use of an abnormal reflex pattern can itself produce physical deformity. Thus, the assessment also encompasses measuring the client's range of motion and determining with some precision to what degree he or she can "fine tune" the movement or movements that might be used as the link between the body and a communication aid.

The choice to be made among many types of interfaces (different sorts of switches, keyboards, head wands, mouthsticks, lightsticks, etc.) often makes assessment difficult. One systematic approach to the problem has been that of Margaret R. Barker of the Rehabilitation Engineering Center, Children's Hospital at Stanford University; and Albert M. Cook of the Assistive Devices Center, California State University, Sacramento (2). In evaluating the physical ability to control assistive aids, these investigators and their colleagues make an inventory of all the anatomic sites where a person can demonstrate purposeful muscular movement and then have the person use those sites to perform such tasks as grasping or squeezing an object. Other factors being equal, hand and finger sites are preferred to sites on the head, and sites on the head to those on the feet. Sites on the legs and arms are least favored because, in general, muscles there are least suited to finely controlled movements.

Once one or more promising anatomic control sites are identified in this manner, the next steps are to determine:

1. how much control (i.e., range and precision of motion) the client can demonstrate with each site;
2. which types of interfaces work best for the person at the potential control sites; and
3. how rapid and accurate the client's movement is at each site and interface combination, and with each combination how quickly the client tires.

This constitutes the first comparative testing of site-interface combinations, which are thus rank ordered. Together with the client's preference, this testing helps the rehabilitation team to avoid guesswork in recommending interface choices and to clearly delineate what tradeoffs should be considered before a final decision is made. Barker and Cook believe that followup evaluations at 3 months, 6 months, and 1 year are critically important. If the initial choice of interface proves disappointing, these evaluations provide the opportunity for adjustment or change.

Considering the client's posture is no less important than considering the interface. Many severely physically disabled nonspeaking people use wheelchairs. This means that unless the client is properly positioned in the chair (by cushions, padding, restraints, straps, etc.) and the placement of the communication aid is made appropriately, the client may be unable to use the aid efficiently.

Unfortunately, many of the current generation of portable communication aids are too bulky, too heavy, or both to be used by those physically disabled nonspeaking persons who can walk. Even when an aid is small enough and light enough for such a client to use when he or she is ambulatory, careful attention must be given to exactly how the client will wear or carry it and to its durability. Ambulatory people with movement disorders are subject to inadvertent collisions with inanimate objects and to frequent falls.

In fact, ease of maintenance and access to timely repairs at moderate cost can make the difference between appropriate and inappropriate devices for all nonspeaking clients, regardless of whether their units are portable. Because many of these devices may be made or serviced far from where the clients live, reliability is also a factor that the assessment team should not overlook. Few, if any, school districts have repair and maintenance staff trained to service high-technology, computer-based communication aids making this the responsibility of manufacturers and distributors who are not always in a position to do the job. Of course, even where there are such services for students, they are not usually available to nonstudent clientele.

Assessment is also directed toward testing a client's actual or potential language skills and his or her style in responding to verbal stimuli and in arranging objects, pictures, symbols, words, or letters into larger units of communication. A client who is to use a scanning device, for instance, must be able to remember what he or she is looking for long enough to find it on a display of multiple-choice items arrayed in rows and columns. No matter what type of communication aid is considered—except perhaps if it is to provide only a choice of "yes" or "no"—the user must be able to discriminate between like and unlike items, to put ideas in logical sequence and to classify.

An important aim is to determine (regardless of how the client was previously able to commu-

nicate) whether the client has receptive language abilities, to what degree, and how best to utilize them. Some nonspeaking persons, for example, are at least temporarily incapable of using the alphabet, and for them a pictorial language like Bliss symbols—also called Blissymbolics—may be either the best language they can master or a way station toward later learning to read and spell (17,24).

Blissymbolics is a graphic, meaning-based system, in use in 15 countries, that enables anyone who can point to a symbol display, or control a device that presents these symbols, to communicate. Because the user selects and transmits the meaning elements of the message—i.e., the symbol—he need not know how to read, spell, or analyze words into their phonetic components. And, because a written word or group of words always accompanies the message, Blissymbolics can be understood by any receiver who can read. Other clients may already know how to read and spell or may show immediate promise of being able to learn to do so. Without appropriate optimal assessment of such language abilities, the chances of an optimal match between client and communication system are remote.

It is important to remember, too, that advances in communication aids are to be expected and that the needs of nonspeaking persons may change over time. For those whose disabilities are likely to be stable—e.g., most persons whose lack of speech is congenital—a trade-in or refitting option could enable them to take advantage of technological improvements as they come along. The communication system that serves a 5-year-old cannot be expected to serve an older child or an adult. Similarly, persons with such progressive disorders as multiple sclerosis or amyotrophic lateral sclerosis (ALS) who today can function with one kind of communication system may need quite another kind as their condition deteriorates, something that can happen in the span of only a few months. Yet insofar as the author could determine, few manufacturers of personal communication aids make provisions for trade-ins or component refitting, and there are few loan or rental banks of these devices organized by hospitals, clinics, voluntary groups, or other community organizations.

Thinking differs as to when in the assessment process it is best to even provisionally expose a client to a choice of commercially available communication aids. In a study of 16 ALS patients in Britain, Perry, Gawel, and Rose recommended "that a 'library' of aids be available to patients so that a good choice may be offered and, as the disease progresses and manual dexterity diminishes, they may exchange one aid, which is no longer appropriate, for another that meets their needs more realistically" (34). This is also the view of many workers at U.S. education and rehabilitation centers who believe that, whatever the reason for their clients' inability to speak, having an array of aids on the premises would not be only advantageous to them, but would also serve to familiarize the staff with the devices on the market and new ones as they are introduced.

There are others, however, who believe such a "library" of aids requires too much financial outlay or is undesirable on other counts. For instance, Bruce Gans, Director of Patient Services at New England Medical Center's Rehabilitation Institute in Boston, believes that "to have an array of technical equipment is a very restrictive approach to the problem (of assessing nonspeaking persons because) you immediately presume that your universe of options is right in front of you. . . . First of all, one must define what the patient's real needs are" (14).

At The Children's Hospital in Boston, Howard Shane, Director of Communication Enhancement, says that a library of devices would not only be expensive and unnecessary, but would take up too much space. Instead, his unit asks distributors to supply videotapes of what their products look like and how they operate so that clients (some of the adults) and their parents can view them. If it is decided that one or another aid may be appropriate, a trial period is arranged before a recommendation is made to purchase (41).

Obviously, this is a controversial topic. It should be reported, therefore, that the Institute of Neurological and Communicative Disorders and Stroke (a part of the National Institutes of Health) has awarded Richard Foulds of the New England Medical Center a contract "to develop a prescriptive assessment system to determine the

characteristics of the device most suitable for a particular patient; to review, using computer software, the various devices available; and then to select that which best matches the necessary specifications. This approach does not require a center to have a large selection of devices on hand." Completion of the project is expected in 1985 (32).

Meanwhile, Shane, like Gans, believes that not having a variety of devices on the premises of an assessment center minimizes the risk of prescribing one when it may be inappropriate or premature. He and his colleague, Anthony S. Bashir, have been particularly interested in persons—most of them cerebral palsied—whose communication disorders are congenital. In this connection, they have developed a branching type assessment matrix for recommending a device or not that takes into account:

1. the age, physical, and intellectual status of the client;
2. other factors, such as whether or not the client has previously had speech therapy; and
3. the family's willingness to allow the child to be fitted with an augmentative communication system (42).

If, despite speech-language therapy, for instance, a 3-year-old is still unable to imitate speech and word sounds with some accuracy, he or she may make greater communication strides by being introduced to an alternative system, which may later facilitate speech development. In a study done at the University of California, Los Angeles, in fact, Laura Meyers found that starting such children with communication aids encouraged development of language and that as the children developed spoken words they dropped them from communication aid use because the spoken word was so much faster (27,28).

On the other hand, many parents find it hard to accept the possibility that their child may never talk. Thus, while it is in one sense to provide a communication aid immediately, professionals sometimes find it prudent to delay the description pending more counseling for the parents. However, as children develop spoken words, they tend to drop them from communication aid use, which parents should be told.

Just as philosophies differ as to whether assessment centers should have libraries of commercially available devices on hand, they also differ as to whether—other considerations being equal—a display or voice output is preferable. Although the situation is subject to change, all off-the-shelf commercially available devices now offer only one or the other capability.

Some speech professionals believe with Professor John Eulenberg of the Artificial Language Laboratory of Michigan State University that, if a client is to have only a single mode of communication, voice output is more likely to facilitate the normal socialization of nonspeaking multiply handicapped persons of any age. Furthermore, most children prefer spoken output. But others are of the opinion that, for children, especially, such a choice is unwise.

Gregg C. Vanderheiden, Director of the Trace Research and Development Center for the Severely Communicatively Handicapped at the University of Wisconsin is among those who represent that opinion (50). According to Vanderheiden,

> It would be good to have voice output as a part of any system. But the key is that, although you can use writing for conversation, you can't use conversation for writing. And, besides, no current voice output system approaches the speed of conversation anyway. Thus, if you are going to have any educational work, any kind of learning, you need to have a system that will enable you to write. In fact, the thing we have to watch out for as voice output systems become cheaper and cheaper is that we don't end up with voice output aids only, thereby ignoring the other communication needs of physically disabled nonspeaking youngsters and so sentencing their futures to dead ends.

On the other hand, many people who once talked and can no longer speak, particularly welcome a speech output device no matter how cumbersome or slow. There are two main problems regarding voice output devices. One is that many physicians are unaware of the existence of these products. (They include two models of the Handi-Voice and the Vois, all distributed by Phonic Ear, Inc., Mill Valley, Calif.; the Express Three made by Prentke-Romich, Shreve, Ohio; the Words Plus device marketed by Words Plus, Sunnyvale,

Calif.; the Dec Talk, a nonportable device marketed by the Digital Equipment Corp., Maynard, Mass.; Vocaid, a product of the Texas Instruments Corp., Dallas, Tex.; and the Form-a-Phrase Possum.)

The other is that the synthetic voice most of these products use is undeniably male. Synthetic female and children's voices are already a reality and are available for some devices, but have yet to be applied to many assistive communication aids because they are technically more difficult to achieve (they take up more memory space on an electronic chip than do male voices) and so are more expensive—though it is thought that advances in chip technology being made by such firms as the Votrex Co. in Troy, Mich., will largely eliminate the cost differential.

Then too, it is not yet clear that a male voice for a child or a woman is necessarily a disadvantage. Some children, for example, apparently like having an adult male voice because it makes them feel important. According to John Eulenberg, of the Artificial Language Laboratory at Michigan State University:

> This is an area that really hasn't been adequately investigated. We are just on the threshold of a period of discovering what the prime factors are in voice output communication aids that are important for personal identification and psychological robustness (10).

PSYCHOLOGICAL ISSUES

While it seems evident that inability to speak, in combination with other disabilities, has profound psychological consequences, this is an area that merits systematic research as it has been little studied to date. For those newly in the ranks of the nonvocal it has been informally observed that, as with any physical handicap, there are sequential stages of denial and isolation, anger, bargaining, depression, and acceptance analogous to the five stages of dying that have been described by Elisabeth Kübler Ross (20). This does not necessarily mean, however, that all those who lose their speech pass through the entire Kübler-Ross-like sequence or want an augmentative communication system even if they do.

At a patient advocacy meeting held in May 1981 at the Northridge Hospital and Medical Center in Northridge, Calif., near Los Angeles, for instance, one young man in his twenties—whose loss of intelligible speech was associated with quadriplegia incurred in a motor vehicle accident over a year earlier—made it clear (through a speech therapist who knew him well enough to decipher his meaning) that he was still too angry at what had befallen him to accept this kind of help. Similarly, a 29-year-old woman with advanced multiple sclerosis that had rendered her speech so ineffective that her meaning had to be guessed at, indicated strongly that she wanted nothing in the way of a technical speech aid.

On the other hand, this kind of response is not universal. At the Clinical Center of the National Institutes of Health, for instance, speech therapist Barbara C. Sonies reports that speech aids for terminal cancer patients unable to talk have made it possible for them to maintain communication with their families. And, this has meant a great deal to those families both when the patients were still alive and when ultimately some died of their disease (44).

Perhaps the most extensive exploration of this topic to date has been made by David Beukelman, speech pathologist in the Department of Rehabilitation Medicine at the University of Washington, in collaboration with Pat Misuda, a speech-language pathologist, and Carole Lossing, an occupational therapist, both at Harbor View Hospital in Seattle (3,5). Their work has been with adult patients in an intensive care unit. Some of these patients have had a chronic degenerative illness, such as ALS, where loss of speech was a direct consequence of the disease process. Others were patients with leukemia and other diagnoses who, in the course of their final hospitalizations, had to be intubated in order to be supported on respirators, which also made speech impossible.

These investigators have found that patients in the terminal stages of an invariably fatal illness do not have the emotional reserves to use an aug-

mentative speech aid unless they have been familiarized with the equipment in advance. Their practice has therefore been to broach the subject with the patient and patient's family well before speech becomes impossible and to introduce them then to the various devices that might be used to compensate for an inability to speak, should it later occur. The patients then have time to learn to use whichever device is likely to be most appropriate (language board, scanning device, direct selection print output device, synthetic speech output device, etc.). If the patients cannot talk when they are dying, many are then able to communicate with the chosen device until a day or two before the end.

Beukelman and his colleagues suggest, therefore, that hospitals keep banks of augmentative speech aids and rent them just as they rent radios or television sets. In their experience, it is not only the intensive care patients dying of protracted illnesses who can benefit, but also intensive care patients with better prospects for recovery but who are temporarily partially paralyzed, or otherwise immobilized, and unable to speak.

Patients in the second situation often become temporarily psychotic, thus complicating their nursing care. For example, a 23-year-old teacher with Guillain-Barré syndrome who had to be supported on a respirator and a 16-year-old boy whose acute cardiac illness necessitated multiple intravenous lines were both hallucinating, having nightmares, and exhibiting other signs of profound disorientation—largely because they could neither speak nor move. As both had limited hand motion, they were provided with the Canon Communicators previously described. Once shown how to use the devices, these patients became calm and rational within hours. The investigators believe that since emergency rooms often treat patients with similar symptoms, augmentative communication aids may also be useful and cost effective in that setting.

In addition to the type of nonvocal persons just discussed, there are those who have been born with serious physical handicaps including the inability to speak. Most of these are diagnostically classified as having one or another form of cerebral palsy (CP). Many of them have little or no voluntary control of motion.

Older CP children and adults who fit this description have become capable of "speaking" and "writing" because of recent advances in communication aids and in computerized communication aids especially. A few, in fact, have been able to complete high school, continue to college, and may even be able to pursue graduate degrees. Microprocessor equipment has allowed them to prepare full sentences and full texts rather than be restricted to simple yes-no or multiple-choice responses. Certainly this should mean that many will become employable and that the pool of such individuals should grow as school systems open up to them so that the onset of their education is not as long delayed.

Still, not all nonvocal CP persons of comparable intellectual ability have been able to master microprocessor equipment when it has been made available. And presumably even those who have achieved such mastery could have done even better had they become familiar with it earlier. It seems reasonable to ascribe this unevenness in aptitude largely to the limited opportunities for cognitive development many CP children have while they are of preschool age (15).

Physical activity under voluntary muscle control is acknowledged to be the foundation on which language is built. Through such activity, young children learn to distinguish self and nonself, the relationships of objects to each other by size, shape, and weight, and to manipulate and control objects and people in their environment. Nonvocal CP children who cannot draw pull toys, cannot activate windup toys, cannot imitate the sounds and the behavior of what they see around them—in short, who cannot on their own explore themselves or the world—tend to come to these and other concepts late if they come to them at all.

Said another way, the mind and body are partners in the cognitive development of the young child. As Goldenberg observes, there is truth to the old proverb: "I hear and I forget; I see and I remember; I do and I understand" (15). Verbal abstractions, while they can and do result in learn-

ing and autonomy, probably do not produce them as efficiently as does the child's physical experience with the world.

Are the disabilities of the nonverbal child largely or wholly remediable before he or she reaches the age when children normally begin to undertake academic work? There is no definitive answer to that question at the present. Nonetheless, preliminary results from several research programs suggest that the answer may be yes. Three such programs will be briefly mentioned here.

One of these is the Intervention Project of the University of California, Los Angeles, directed by Laura F. Meyers, an early language development specialist. In a pilot project conducted in 1980 and 1981, Meyers and her colleagues worked with six nonverbal children (four boys and two girls) whose handicaps included mild to severe cerebral palsy, Down's syndrome, developmental delay, and expressive language problems, and who were 27- to 37-months old when the study began (27,28).

Four different commercially available assistive communication aids were introduced to the children to determine if the devices would increase their use of oral and gestural language and would expand the number of words they used. It was also thought that this strategy might improve the youngsters' attention spans, scanning skills, and eye-hand coordination, as well as present them with an opportunity to learn first-hand about the principle of cause and effect.

All these expectations were confirmed to a greater extent than had been anticipated. However, gains were greater when the children used the HandiVoice 110, which has a synthetic speech output, than when they worked with the three other devices that offered only visual displays. One child, for example, who had learned only 10 words during a whole year of previous speech therapy imitated and said 25 new words during the very first session he "met" with the HandiVoice. Meyers believes that the critical factors in such improvement were the children's control of speech output, the reward of hearing what they wanted to say spoken exactly the same way each time, and the fact that the children felt less threatened by a machine than they would have by an adult who wanted them to perform.

A second example of successful training of the nonvocal has been observed using the "Turtle," a computerized robot toy retailing for about $600, which is manufactured for schools by Terrapin, Inc., in Cambridge, Mass. By linking the toy to a larger computer to augment its "brain power," E. Paul Goldenberg and his colleagues made it briefly available to severely handicapped nonvocal children, who could make it respond to their commands by operating a switch that was appropriately configured and engineered (15).

Ordinarily, for example, these children were unable to knock over a pile of blocks. But when the turtle was programed with the proper software (easily written in any of several computer languages), they were able to guide the robot across the floor to do exactly that. Moreover, by fitting the turtle with a pen, the children were able to instruct the toy to draw whatever they wished—whether something they had actually seen or a fantasy design—on a piece of paper taped to a table or the floor. The phrase "whatever they wished" is key.

A device such as the robot gives the child a chance to initiate play experiences rather than merely follow the suggestions or requests of others, a situation that fosters autonomy and education readiness. It may also reveal aspects of the child's potential that would otherwise go unnoticed. The manner in which a child comes up with an idea and generates plans accordingly, as demonstrated by his interactions with this sort of equipment, provides insights into his capabilities that probably could not be obtained by other means.

Although Goldenberg reports that the robot Turtle has been used primarily with older handicapped children and adolescents, robot toys in conjunction with computers could very likely be employed to give many preschool nonvocal CP children an early advantage in developing their cognitive and language skills. While some might object to this arrangement as too costly, the price of microprocessor components is dropping, and the potential savings of reduced special education and institutionalization are appreciable Estimates of the costs of lifetime institutionalization for a totally disabled person start at $500,000 and go up.

The early development of motor-thinking skills in this particular disabled population was also to have been the focus of a 4-year computer-assisted research project that had been approved for funding by the Department of Education but was suspended because of budgetary constraints before full implementation (52). The multidisciplinary team at the Child Development and Mental Retardation Center at the University of Washington headed by Wesley R. Wilson, had planned to:

1. analyze the motor-thinking elements required by users of communication devices, and educational computer programs, both current and proposed; and
2. develop a set of graduated motor-thinking tasks and corresponding software programs for the Apple II personal computer that the preschool children participating in the project could operate with a single switch.

Wilson and his colleagues had thought that the sequences of games and other play opportunities offered by the software programs would stimulate the intellectual maturation of the handicapped by providing them some of the experiences of their nonhandicapped peers, experiences that they are unable to have on their own. They had planned to use color, graphics, action, and sound as stimuli, feedback, and rewards. While it remains to be seen how effectively computers can substitute for normal sensory-motor activities, it would not be surprising if early familiarization with microprocessor technology accelerated the ordinarily delayed rate of learning of nonvocal children and facilitated their eventual integration into "regular" classrooms.

If so, the planned project, if it is ever implemented could be readily repeated: the more so because the Apple II, retailing at about $2,000 is moderately priced, as personal computers go, and so are most of its necessary accessories. Once designed and tested, it was expected that the special computer software would be relatively inexpensive, too. Since there is now very little educational and recreational software for disabled children below the fifth grade, Wilson and his colleagues believe there would be a sizable market for the programs they had in mind.

TRAINING AND RESEARCH ISSUES RELEVANT TO THE LIMITATION OF CURRENT ASSISTIVE COMMUNICATION AIDS

The mastery of many technologies for handicapped people is fairly straightforward. While it takes some getting used to, for example, walking on crutches holds few mysteries. And once familiar with motorized wheelchairs, users need do little more than turn them on and off and steer them to have them under control.

Not so with assistive communication aids for the severely physically disabled who cannot talk. Because of the complexities of language, because of the limitations of these aids in the face of such complexities, and—most of all—because communication is a dynamic process between sender and receiver, learning to operate these devices is only the beginning of a far more demanding task.

Normal speech proceeds at a rate of about 100 to 200 words per minute, whereas an output of 2 to 10 words per minute is usually the best that can be attained with the present generation of commercially available augmentative communication systems. This disparity requires accommodation by the nonvocal and their audiences alike. As one researcher in the field has put it:

> We have concentrated so much on giving individuals an aid that will let them get a word or words out with printed output or high technology voice output that we've sometimes completely forgotten that it is not nearly so much one mode of expression or another that makes it hard for these people to communicate as that all modes—whether they are simple language boards or entail the use of highly sophisticated electronics—are slow (52).

In addition, most communication aids have displays, electronic memories, or both that restrict the size of their vocabularies. This means that some things a normal speaker would say directly must be said in a more round-about way by the users of these aids, while there are other things

that they can only hint at, and still others that they cannot say at all.

The fixed vocabularies characteristic of many of the devices also require compromises with grammar and syntax. The result, at times, is a staccato or "broken English" effect. To be sure, some models can be made to communicate anything. But they do so only if the user makes a laborious effort to string the message together letter-by-letter or phoneme-by-phoneme (a phoneme is a unit of sound such as the "f" sound of "ph" or the "sh" sound of "tion").

Unless given the opportunity to compose the text in advance, nonvocal people are thus at risk of losing their audiences by the time they can communicate. Or the audience may become sufficiently impatient to guess the message—not always correctly—before a person has the chance to fully convey what he or she has in mind.

But it can be as difficult for those in the company of the nonvocal as for the nonvocal themselves to make optimal use of assistive communication aids. This is particularly true in school settings where there are speaking and nonspeaking students in the same class. Teachers tend to be inhibited by children who cannot talk and at a loss as to how to enable them to compete with their orally fluent peers during classroom activities. All too often nonverbal youngsters do little else but watch and listen while they are in school.

Can speaking and nonspeaking children be taught in the same classroom without the latter being merely bystanders? The answer appears to be yes (15). But only if teachers take on the task with adequate preparation and ongoing support.

One of several examples is the Loma Linda University's Medical Center Augmentative Communication Model Program, funded by the Office of Special Education of the Department of Education, which operated in schools for the orthopedically handicapped in two California counties (Riverside and San Bernardino) from September 1979 through August 1982 (11). Through this program, a team of speech-language pathologists went into the schools to show teachers how to assess nonoral children, how to adapt workbooks and other curricular materials for their use, and how to conduct classes so that the nonspeaking pupils as well as the speaking ones could participate.

Thus, the integration of nonspeaking and speaking persons in group situations appears a feasible goal, but not one achieved without effort. Whether it can be accomplished through instructional manuals rather than through the actual presence of specialized and experienced personnel is a question still to be resolved.

In general, while augmentative speech systems are obviously a great deal better than nothing, they are, as Arlene Kraat has pointed out, "only vehicles through which communication and (social) interaction can be achieved" (19). Without training a client in strategies aimed at those objectives, an aid is unlikely to be put to optimal use, even when well matched to a highly motivated user. Developing and refining these strategies is a major research need. So much emphasis has been put on the devices themselves that there is a dearth of information about how to make them actually compensate for an inability to communicate.

More active participation of severely physically handicapped nonvocal people themselves early in the research and development process would probably help in this regard. No matter how well-intentioned, able-bodied professionals simply cannot adequately simulate or assess what such disabled nonspeaking persons actually experience. Keeping in mind that blind engineers helped to produce some of the recent advances for the blind and severely visually impaired, it may be advisable to encourage members of the nonspeaking population to become engineers, linguists, speech-language pathologists, and so forth, if rapid progress is to be made in this field.

It may be, too, that there has been too much stress on those assistive communication devices that have the most sophisticated engineering and electronics. It is not only that they are costly, but also that the technical assistance that is needed to modify and repair them is not always readily available. The author of this study was often told that more research attention should be directed to simple and middle range aids and imaginative

techniques to enhance their effectiveness. It is not that speech-language professionals believe that the effort should be abandoned to develop better high-technology and more sophisticated replacements for speech for the multiply handicapped nonvocal. That there is plenty of room for improvement is obvious. But, at the same time, they believe that much could be accomplished by fuller and more ingenious exploitation of existing aids and technologies. An example of one problem and one uncomplicated solution to it may make this issue clearer (47).

The problem is that a small child for whom the best way to point is with a regular headstick often cannot use one unless it is so short that it will point only to things at very close range and within a very limited arc. Small lightweight optical lightsticks or lightpens fastened to the head are one answer to this frequently encountered problem. Because their beams go on for a considerable distance before they fade out, these devices can serve as pointers, allowing users to indicate an object whether it is right in front of them or at the other end of the room.

More than mere convenience can ride on this kind of flexibility. A severely physically disabled nonvocal toddler can be asked at supper whether he wants, say, a bite of hamburger or a bite of baked potato next, and using the lightstick, he can respond no matter where on the plate those items are. The choice this permits him in controlling his environment—despite the fact that he may have to be fed by someone else—fosters a sense of independence that is an important part of nourishing his self-esteem.

Whatever the age of the assistive communication aid client, strategic training considerations include the following:

- assessing the match between the aid and the potential user's motivations and abilities;
- considering the communication content of the aid. Persons with some kind of brain injury communicate more effectively with symbolic or picture "languages" than with traditional alphabetic systems. Whether symbolic, pictorial, or orthographic, vocabularies need to be suited to the user;
- preparing the user, who has an acquired speech loss, to accept the constraints on his expression that the aid imposes and to compensate for them by: 1) preparing texts in advance when possible, 2) saying things more concisely, and 3) expecting prediction and anticipation from listeners;
- teaching the nonspeaking child or adult who has never acquired speech to use language by building on his earlier experience and longstanding patterns of behavior, emphasizing particularly what to talk about and starting and maintaining conversations;
- stressing flexibility by encouraging users to switch communication tactics when one proves ineffective; and
- making social interaction a higher priority than perfection of grammar, syntax, or vocabulary (32).

Last, but not least, training ideally should address the environment as well as the user. In other words, it should also concern itself with the speaking community. Speaking partners of nonvocal persons can often learn techniques that make communication more efficient and effective. As already mentioned, such cooperation is crucial in schools, but is also important in employment settings and for families, attendants, and friends.

THE COMPATIBILITY OF SYSTEM COMPONENTS

The effectiveness of commercially available assistive communication aids is not only a factor of how well the client has been fitted for an augmentative speech system, but also the construction, operation, and design of the equipment itself. However well a device works for a given user,

it is often hard to identify which of its characteristics have contributed to the result unless baseline and followup data from field studies are available.

Efforts to collect such data are only just beginning. The most ambitious field study to date is in progress at the Assistive Devices Center of the School of Engineering at California State University, Sacramento, under the direction of Albert M. Cook. The Center follows clients at 3-, 6-, and 12-month intervals and has produced reports (published individually) on nine assistive communication aids as a result. Some of the findings have been incorporated into product design modifications by manufacturers (7). More of such studies are desirable both for the information of nonvocal persons and for that of third-party payers, who are understandably in need of persuasive evidence that investment in these technologies is worthwhile.

A related problem is the frequent lack of compatibility among the various electronic communication systems and environmental control aids with interfacing switches and accessories. Vanderheiden and his colleagues point out that "as might be expected, nearly every researcher and manufacturer chose a slightly different connector, pin-out, voltage convention or format . . . (with the end result often being) that the handicapped individual is fitted with an aid, interface, and accessories which do not fit together well" (45).

To remedy the situation, the International Standard Interconnection Task Force was organized in December 1980. This task force, composed of clinicians, manufacturers, and researchers from the United States, Canada, and Europe, has the following objectives:

- develop a common technical format for aids and interfaces;
- develop a common connector or connectors for those components; and
- develop a simple, readily understood naming format that will enable people not technically trained to mix and match aids, interface, and accessories to meet the needs of handicapped individuals.

The task force has its headquarters at the Trace Research and Development Center for the Severely Communicatively Handicapped at the University of Wisconsin-Madison. It is funded by the National Science Foundation.

4.
Information and Funding for the Speech-Impaired

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INFORMATION RESOURCES

Ready access to information about appropriate aids and techniques is vital if the needs of the handicapped population are to be met. How well are severely physically disabled nonvocal persons served in this regard? The author of this study has found that, although major steps have been taken to obtain information on this population—information which was almost wholly lacking as recently as the mid-1970's—incomplete and fragmented data collection and dissemination efforts continue to be a major problem.

Some information resources on the disabled nonvocal include the following:

1. *ABLEDATA.*—This is a computer data base, funded by the National Institute of Handicapped Research and headquarters at the National Rehabilitation Information Center at Catholic University in Washington, D.C. Its capsulized contents are made available to interested parties through information brokers whose names the Center gives to prospective clients (anyone who needs the information) on request. The system has been plagued by poor funding, a situation reflected in its print-outs on communication aids. While they do provide descriptions, price, and manufacturer information regarding many systems, not all aids are included in its listings and reports on those that are included may not always be entirely up to date.
2. *The Non-Vocal Communication Resource Book.*—University Park Press, Baltimore, $15.95; yearly updates for this looseleaf binder volume are $7.50. Compiled by the Trace Research and Development Center for the Severely Communicatively Handicapped at the University of Wisconsin-Madison, this illustrated volume—funded in part by the Federal Government and in part by the United Cerebral Palsy Research and Education Foundation in New York—is the most comprehensive reference in the field. It offers speech professionals, educators, parents, and administrators concise information about: 1) commercially available devices and their prices; 2) some communication systems under development in research settings; 3) devices that are not commercially available, but nonetheless are readily duplicated by, say engineers affiliated with the special education unit of a school district, perhaps through a public-spirited church or civic group; 4) an interface switch profile and annotated list of commercial switches; and 5) a bibliography. The book, however, does not pretend to be all inclusive and is really best described as a very good catalog. Thus, for example, it provides little or no information about the strengths and shortcomings of given devices. Nor does it discuss the extent to which any device has been tested in the field, the clients involved, and the results obtained.
3. *Trace Center International Software Registry: Programs for Handicapped Individuals.*—Issued in January 1982, this registry, whose initial cost is $12 and for which there will be periodic addenda, should serve as a clearinghouse for information on computer-assisted educational and recreational materials. The registry lists descriptions of the programs, manuals for the programs, computer requirements for the programs, etc. The reader is also able to learn from the registry the prices of the programs and from whom he may order them. Home hobbyists and others who have developed programs, but who do not have the facilities for manufacturing them, are invited to submit entries. The only proviso is that they permit the Trace Center to duplicate and

disseminate their products at cost. As in the *Non-Vocal Communication Resource Book*, no attempt will be made in this registry to evaluate materials described.

4. *Communication Outlook.*—This quarterly newsletter, published by the Artificial Language Laboratory at Michigan State University jointly with the Trace Center at the University of Wisconsin at Madison, the official publication of the International Society for Augmentative and Alternative Communication. It "is addressed to the community of individuals interested in the application of technology to the needs of persons who experience communication handicaps due to neurological or neuromuscular conditions." The newsletter is an invaluable source of information, providing its readers with news about the delivery of clients' services and about individual users, as well as about the communication aids themselves.

   Communication Outlook accepts advertising and has about 2,000 subscribers who pay $12 a year to receive it. In addition, it is distributed to several thousand other people through a variety of channels. As the first international journal to have brought together professionals in disciplines that participate in the communication aids field and their clients, it has also published a comprehensive bibliography dealing with the many issues involved. The bibliography is available in printed form and also as an updatable and queriable data base on computer diskettes, containing a program that allows users to selectively generate subsets of the bibliography that particularly meets their needs. The bibliography can also be accessed with Radio Shack TRS 8-III and Apple II computers. Annual updating is planned.
5. *Features of Commercially Available Communication Aids.*—A wall-chart listing of both portable and nonportable aids. It is prepared by Arlene Kraat of the Queens College (New York) Speech and Hearing Center. It covers communication output factors, selection factors, portability, and distribution sources. It is available from Prentke-Romich Co.; 8769 Township Rd., 513; Shreve, Ohio 44676.

OTHER SOURCES OF INFORMATION

While professional journals like those of the American-Speech-Language-Hearing Association (ASHA) (which has a circulation of about 40,000) and the Journal of the Institute of Electrical and Electronics Engineers (which has a worldwide circulation of about 50,000), do carry relevant material, it is on a sporadic basis. Besides, there is no guarantee that these journals will be read by certain audiences—nurses and physicians, for example—who need to be informed about the subject.

Much the same is true of a wide spectrum of other publications that are intended as much for the laity as for professionals. *Echo On*, a newsletter published by Phonic Ear, Inc., in Mill Valley, Calif., is an example of such a publication. Its primary purpose is to publicize the use of the synthetic voice products the company markets for the nonvocal (i.e., two models of the HandiVoice and the Vois). It also occasionally covers topics of related interest, such as assessment and training. But, as is typical of a newsletter, its articles are necessarily brief and anecdotal. While they do provide readers with ideas, their usefulness to professionals and their clients is still limited.

Funding constraints having adversely affected both periodicals and the compilation of catalogs, registries, and bibliographies in this field, and also the publication of conference proceedings. For example, the proceedings of a conference on voice output communication aids that was held at the Center for Independent Living in Palo Alto, Calif., in spring 1980 under a National Science Foundation award to Telesensory Systems, Inc., of Palo Alto have yet to be published. Because the award allotted no funds to organize or disseminate the products of the conference, these materials have been put into storage and are not available,

although a few of the papers can be obtained with effort from individual contributors.

In time some of the missing information may be supplied by alternative means under entirely different kinds of auspices.

A prime example is CONFER, a computerized teleconferencng system, designed by Robert Parnes at the University of Michigan, Ann Arbor and organized by Shirley McNaughton at the Blissymbolics Institute in Toronto during 1983 (26). Using a computer at Wayne State University in Detroit, the system allows communication aids professionals and anyone—vocal or nonvocal—with an interest in the field who has local access to a computer and model telephone device to have the same kind of interaction they would have at a conference. Thus, one can send "items" via the Wayne State Computer and telephone to the entire group of people who belong to CONFER or direct messages only to particular members of CONFER. There is an initial charge of $50 for this service and any additional charges are made as more than $50 worth of service is used. Billing is handled by the Blissymbolics Institute.

Similarly, in 1981, the National Association of State Directors of Special Education (abbreviated as NASDSE and headquartered in Washington, D.C.) opened Special Net, a 24-hour-a-day, 7-day-a-week, telephone-access computerized news service, that has a number of "bulletin boards," and serves 22 States so far.

At present, the $200-a-year service heavily emphasizes legislative developments and other policy issues in its bulletins to administrators in the special education field. However, it is hoped that, as additional subscribers are attracted to the service, the service's scope will expand to provide more bulletins focusing on matters of immediate practical action for special education teachers and their students. NASDSE may eventually start a second computerized network to deal specifically with rehabilitation topics. If so, membership will likely extend to any organization with relevant concerns and perhaps even to individual professionals (43).

At least one organization concerned with the needs of individual handicapped persons has already tied into the existing NASDSE network. The California Repository for the Handicapped located in Sacramento has a "bulletin board" that runs want ads on devices needed and devices available, whether new or secondhand. At present its coverage is pretty much confined to the blind portion of the handicapped community in northern California. But there seems little reason why other "bulletin boards" could not be organized regionally to serve a wider spectrum of needs.

FUNDING ISSUES

On May 3, 1981, a Chicago jury awarded 46-year-old Eileen Tannebaum $6.5 million and her husband, Louis, an additional $2.5 million for injuries she incurred during surgery that left her a quadriplegic and unable to talk (37). Some of the $8 million for which the case was ultimately settled was used to provide Mrs. Tannebaum a customized communication system, designed by the Artificial Language Laboratory at Michigan State University (10). Although larger than most, this is one of several medical malpractice and personal injury settlements the author of this study identified that has been used to underwrite customized assistive communication aids technologies.

However, the disabilities of most severely disabled nonvocal persons are not the result of medical malpractice, and so these people do not have access to this resource. Nor do they usually have extensive personal financial means. They and their families therefore heavily depend on traditional third-party payers as sources of funds for communication aids. The following federally assisted and private programs are those pertinent to consider in this regard.

Medicare

It might be expected that both persons who are over 65 and those who are chronically disabled would be eligible for payment under terms of the law. In practice, Medicare has funded communication devices for nonvocal individuals also unable to write only for use in a hospital or skilled nursing facility to communicate with staff—in other words only under Part A of the Medicare law. In no instance has the Social Security Administration's Health Care Financing Administration authorized purchase of such devices under Part B of the law, which would permit Medicare beneficiaries to make these prostheses part of their everyday lives (10).

Medicaid

Though this program for the indigent and medically needy is through Federal-State partnership, decisions are made at the level of State or county by State or county personnel. Medicaid has covered communication aids in several States, including California, Oregon, Washington, Wisconsin, Illinois, Colorado, New Jersey, Massachusetts, and New York. In some States, however, there has been no such coverage, and even in those States where there has been coverage, it has not necessarily been in all locales. Approval or disapproval of reimbursement is largely based on the decisionmaker's personal interpretation of guidelines, if any, that may be available. Any funding that is made often takes months or years to obtain. Clients often face many refusals and must go through repeated hearing processes to have a chance to succeed (38).

Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)

Coverage for assistive communication devices is specifically excluded from the so-called basic program that pays for medically necessary services and supplies for the dependents of active duty or retired military personnel. They also "generally do not qualify" for cost-sharing under the CHAMPUS program for the handicapped that provides financial assistance to active duty members for the care, training, and rehabilitation of a spouse or child who is seriously physically handicapped or moderately or severely mentally retarded. Some exceptions have been made to provide *basic* communication necessary to accomplish training or teaching of a seriously handicapped individual (13).

Crippled Children's Services

Like those of Medicaid, these services are administered under a Federal-State partnership, and like that of Medicaid, funding by locale (38). Thus, payment has been provided in some States, but not others, and in parts of some States, but not all parts. Again, long delays between requests for funding and the actual provision of it often cause postponements of months to a year or more. Moreover, some crippled children's agencies will pay indefinitely for traditional speech therapy, but not for augmentative aids, even though a client fails to make noticeable progress in traditional therapy (33).

Social Security Insurance and Social Security Disability Insurance

These programs provide direct financial assistance to eligible disabled individuals. Insofar as the author of this study could determine, neither has allowed reimbursement for communication aids.

Public Law 94-142—Education for All Handicapped Children Act of 1975

Under this act, State funds for the education of handicapped children and related services are

supplemented by Federal grant, providing that school districts meet certain requirements. Funding for assistive communication devices varies by State and by school district. Funding has been obtained either on the basis of a child's individual education plan (IEP) as required by the law, or from the local education agency, without reference to the IEP. However, the emphasis in the law is on "specially designed instruction," so that it is not entirely clear whether payment is to be made for devices that make that instruction possible. Thus, some school districts and local education agencies have funded assistive devices and others have refused to do so. When funded under Public Law 94-142, equipment is only for classroom and homework use; it is generally not available to beneficiaries during vacations. Public Law 89-313 is similar to Public Law 94-142 except that the beneficiaries it concerns are enrolled in State-supported or State-operated schools.

Vocational Rehabilitation

Like Medicaid, vocational rehabilitation is another of the federally assisted, but State-administered programs. The emphasis in its funding is on whether the requested device will enhance an individual's employability. Programs in California, New York, Massachusetts, and Oregon are known to have reimbursed. However, there may well be States that have denied funding, and if the severely handicapped client in question has no relatively near-term prospects of employment, denial is usually certain.

Veterans Administration

The Veterans Administration will fund any communication device prescribed for a person who has a "service connected disability." Should the individual's inability to speak not be "service connected," funding for evaluation may be obtained through the Administration's Prosthetics Evaluation Centers. In such cases payment for the actual purchase of equipment is sometimes provided and sometimes not.

Private Health Insurance Sources

Private health insurance sources include the various Blue Cross-Blue Shield plans and the commercial carriers of health and accident insurance. Their funding of assistive communication devices in general depends on the terms of the policy and the nature of the disability. A growing number of companies are beginning to offer reimbursement for such devices, particularly if the severely physically disabled nonvocal person has major medical coverage. But some companies (both the "Blues" and commercial carriers) do so only on a case-by-case basis, while others do so under some of their contracts but not others, and still others do not do so at all. The various field offices of some companies seem to have considerable latitude in interpreting policy contracts, so that even a carrier whose overall policy is to provide payment may not do so in all locales.

Private Disability Insurance

These policies are written by commercial carriers. Chances of their covering assistive communications equipment are good if the aid in question will permit a person to work or will reduce the costs of his care; otherwise, they are not.

Workers' Compensation

Workers' compensation provisions vary by State. In most States persons eligible for coverage who need assistive communication devices are able to obtain funding if the equipment: 1) seems likely to permit them to return to work, or 2) results in less need for attendant care. The second is a consideration only in workers' compensation cases because it involves a potential cost saving to the insurer. Others types of health or disability insurance generally do not pay for the hire of attendants.

Unions and Employers

Both unions and employers may consider funding communication equipment if evidence is furnished that such equipment will improve the in-

dividual's ability to function on the job. Unions have purchased assistive communication devices in California and New York (39). In principle at least, employers receiving Federal financial assistance may be required to provide a communication device as a "job accommodation" or "job modification."

Service Clubs

Groups like the Lions, Kiwanis, Moose, Sertoma, and Rotary clubs have an interest in serving the community and have specifically shown a concern for the handicapped. However, their funding of assistive communication devices is only done case by case.

Voluntary Health Agencies

The Muscular Dystrophy Association in New York City has a loan bank of communication devices that is available to individuals who have a neurological or neuromuscular disorder that results in loss of speech. However, in 1981, the association decided that no device costing more than $100 would be added to the bank. It will keep those more sophisticated and more costly devices it already has, but in the future will purchase only simpler aids such as language boards. Insofar as the author of this study could determine, this organization is one of the only two voluntary health agencies that has gone even this far (48). The National ALS Foundation manufactures, markets, and services a communication aid called the ETRAN Communicator (which helps the user to communicate with eye movements and sells for about $20).

No voluntary health agency identified by this case study includes assistive communication devices in its authorized programs of service. Some do offer information to clients and their clinicians on possible sources of funding and regarding what arguments to make on behalf of applications (39). Occasionally, a voluntary health organization has paid the balance of the bill for a communication aid when, as is usually the case, a traditional third-party payer will not pay the full amount and no other source of funding can be found (6).

DISCUSSION OF FUNDING ISSUES

There is an old axiom in medicine that when there are many different treatments for the same disorder the likelihood is that none of them works very well. From the perspective of the severely physically disabled nonvocal person, the same principle applies in finding a payment mechanism for the assistive communication device that will meet his needs: the many potential sources for funding disguise the reality that reimbursement can be very difficult and sometimes impossible to obtain. Because no single agency in government or the private sector is specifically authorized to assist this population, all tend to say it is not their responsibility and try to shift that responsibility elsewhere.

Little statistical information has been collected on the number of people who have obtained coverage or been denied coverage for these devices by third-party payers. Obtaining an approximately accurate count is, in fact, a major research need.

Nonetheless, it is evident that funding disapprovals are a major barrier to the rehabilitation of the multiply physically handicapped nonspeaking population and to manufacturers' development of assistive communication devices. (More will be said about this in the section, *The Industry Perspective*.) It is also obvious that third-party payers' philosophies are frequently: 1) inconsistent or arbitrary, 2) not necessarily based on rational premises, or 3) both.

In its administration of Medicare, for instance, the Health Care Financing Administration (HCFA), which sets payment policy for the program, does not cover assistive communication devices of the types this case study discusses for beneficiaries who could be expected to use them outside a hospital or skilled nursing home. HCFA's reason for the refusal is that this equipment "does not replace an internal body organ or the function thereof" (6). The paradox is that HCFA routinely approves

payments for electrolarynxes for cancer patients whose loss of speech is due to surgical removal of the natural voice box.

Like that of the assistive aids in question, the purpose of these hand-held devices is to enable patients to communicate for socialization, self-care, health care, and, when possible, employment. Thus, the significant difference between the two classes of prostheses—one for patients with cancer of the larynx, the other for patients with a variety of other diagnoses—is obscure because both are means to the same ends.

The word "prosthesis" is, in fact, a term that third-party payers have referred to in refusing to reimburse the purchase of assistive communication aids. This rationale has been that the Food and Drug Administration's (FDA) Bureau of Medical Devices does not define communication aids as prostheses—as artificial devices to replace a missing part of the body. But again, the agency does so define electrolarynxes, and again, whether by Medicare or some other third-party payers, denials of requests for the funding of electrolarynxes are rare.

When FDA was asked why it considers electrolarynxes to be prostheses and assistive communication aids not, the Chief of the Neurological Devices Branch in FDA's Bureau of Medical Devices replied that the term had been avoided not because the agency truly believes that the second sort of technology is not prosthetic, but rather to avoid regulating it (31). He said that such regulation had been judged unnecessary from the standpoint of safety, and that it would impose a needless burden on a fledging industry. Ironically, that FDA decision would seem to have contributed itself to burdening the industry, as denials for reimbursement based on this lack of definition have caused manufacturers and distributors to lose potential sales.

Another term that is often mentioned in denying reimbursement is "medical necessity." In contrast to electrolarynxes and certain other forms of durable medical equipment (wheelchairs, for instance), assistive communication devices are often perceived by third-party payers as only "patient conveniences" and are therefore ruled out for coverage. As most of the target population are essentially immobile and thus helpless in an emergency if they cannot communicate, the validity of this argument seems dubious.

The impression of the author of this study is that many third-party payers will present almost any reason to deny a request for the purchase of an assistive communication device. The author was repeatedly told by manufacturers, by professionals in this field, and by affected individuals and their families that third-party payers in the health field often take the stance that this equipment should be paid for by programs whose primary purpose is educational or vocational whereas programs with those missions tend to tell them that the responsibility properly belongs to organizations that underwrite health care. Some third-party payers, in fact, have confided to providers that they fear there may be so many nonvocal persons in the population that to provide all of them with remediation would be to break the bank.

Clearly, one reason for the problem of funding is that at a time of fiscal constraint there is an understandable emphasis on holding down costs, and expenditures for equipment are often slashed from budgets first. Another is that the behavior of personnel in the field office of third-party payers—particularly those in the private sector—may not represent the attitudes of the home office management. The varied fates that await funding applications for assistive communication devices seem to reflect different values in different locales, at least where traditional third-party health payers other than Medicare (i.e., Blue Cross-Blue Shield, commercial health and accident plans, Medicaid, Crippled Children's Services, etc.) are concerned. There was ample anecdotal evidence of this in interviews the author conducted in Massachusetts, Michigan, Wisconsin, and the State of Washington.

This evidence was supported by the preliminary results of a study being conducted under a grant from the National Institute of Handicapped Research (an agency of the Department of Education) by David Beukelman of the Department of Rehabilitation Medicine at the University of Washington (4).

Beukelman is in the process of looking at the outcomes of about 200 applications for the funding of communication aids that have been made to traditional third-party payers. He is collecting his data from hospitals, nursing homes, device manufacturers, and individual speech and occupational therapists in private practice and school districts, and has arranged his collection system so as to protect client confidentiality and to prevent any claim filed on behalf of a client being counted twice. While his study sample is being drawn exclusively from Washington, Oregon, California, Alaska, and Idaho—with emphasis on the first of those States—it is a sample large enough so that it may be representative of trends in the Nation as a whole.

With the exception of Medicare, Beukelman has found that no third-party payer has a standard payment policy for these devices; rather, a diversity of attitudes is found among funding agencies, according to locale. In the State of Washington, for example, his data indicate that it has generally been easier to obtain communication aid payments for adults—particularly those aged 20 to 40—whose loss of speech is acquired than for children or adults whose inability to speak is traceable to a condition present from birth. In this case, potential prospects for employment in the near future appear to take precedence over the eventual employability and generally greater life expectancies of nonspeaking persons who are not yet old enough to leave school. On the other hand, the situation in California seems to be somewhat reversed.

Beukelman reports that his data from that State are too sparse to be reliably indicative of funding trends. But Montgomery and Hansen have found that California third-party payers, while generally unwilling to fund applications made on the behalf of young children, tend to approve those submitted for clients aged 15 to 25 who are still in school—presumably because they are on the verge of entering the labor market and can have little hope of being employed without some means to communicate.

Less surprising, perhaps, is that the cost of the communication device or communication system is, according to Beukelman's data, a major factor in determining whether a funding application is approved. Still, Beukelman has found that acceptance or rejection of a claim is not wholly a matter of equipment expense. Instead, success often depends on who is doing the asking and how strongly and persistently.

A request made on behalf of the patient by a physician, for instance, is often more readily honored by a third-party payer than one made by a speech or occupational therapist, even though these allied health professionals are generally more knowledgeable in the area than are most M.D.'s. (Although, the habit many physicians have of merely scribbling the name of the device requested on a prescription blank appears to be associated with a high rate of rejection for reimbursement.)

Similarly, supporting letters funding request to third-party payers that emanate from health professionals based at hospitals with established reputations for dealing with the target patient population are, for the most part, according to Beukelman's preliminary findings, taken more seriously than those from their counterparts primarily affiliated with nursing homes or convalescent facilities.

Other considerations in funding include the fact that applications have a greater likelihood of success when they are accompanied by supporting letters offering persuasive evidence that the device will enable the patient to function more independently and at less cost to all concerned.* When the claim submitted is for something with which they are generally unfamiliar, the processing costs rise accordingly since more time has to be spent in validating its legitimacy. Thus, rather than spend time and money, it is often more cost effective from the insurer's point of view to withhold approval of the request.

As all this suggests that assistive communication devices and communication systems are at a disadvantage in the reimbursement process because unlike the electrolarynx and certain other forms of medical equipment—they are recently introduced technologies. Not all health care tech-

*Also, third-party payers are understandably concerned about the cost of processing claims.

nologies of recent origin, however, are similarly disadvantaged. Thus, the explanation cannot lie in novelty alone. What other factors are at work?

One of these, surely, is that these technologies are not only new, but also very different from predecessor technologies in terms of the patient population they serve. Third-party payers are far more accustomed to reimbursing claims submitted in connection with acute episodic bouts of illness (and with illness requiring surgery in particular) than they are to honoring those for remediating a condition in a person who is disabled, but not necessarily sick. The distinction is pertinent because it means that providers cannot easily submit bills for rehabilitation services and technologies—as they sometimes can with technologies associated with acute illness—in the guise of their being for practices and equipment traditionally reimbursed.

Probably more important is that assistive communication devices and systems are unfamiliar or unknown to most physicians. Rehabilitation medicine is, in general, a neglected topic both in undergraduate and graduate medical education where the thrust is more towards specialties and subspecialties dealing with the application of discrete technologies to particular organ systems than toward improving overall patient functioning. Very little course time is devoted to multiple physical disabilities and to multiple physical disabilities in conjunction with speech impairment, even for recently trained pediatricians and neurologists whose educational philosophies acknowledge the importance of the development of language and speech (12).

Moreover, physicians in the field of rehabilitation medicine, and thus likely to be aware of augmentative communication technology, are relatively few and not especially prestigious in the eyes of practitioners in more mainstream specialties such as surgery, internal medicine, family practice, pediatrics, etc. Rehabilitation specialists thus do not have a great deal of influence on their colleagues in other fields.

These factors together have also conspired to give assistive communication technology little visibility in the medical literature. The publications with the widest physician readership such as *The Journal of the American Medical Association, The New England Journal of Medicine,* and others, rarely, if ever, deal with this subject matter. Nor does their advertising. Thus, there is almost nothing in the professional environment of most physicians that would bring their attention to these issues. Since they have also received little attention from the lay media, there is little impetus for change from that direction either.

The reimbursement of assistive communication devices and systems is further complicated by the role, somewhat down the health care hierarchy, of speech-language pathologists. Though they have knowledge and skills that are of special value to communicatively impaired people, they have struggled for recognition as professionals and against the threat of their functions being usurped by physicians.

Many physicians remain suspicious of speech-language pathologists if for no other reason than that they are generally trained by the faculties of schools of the arts and sciences, rather than by the faculties of medical schools. From the perspective of the physician, this makes them appear less rigorously trained and, therefore, less than full health professionals—an attitude that is reinforced by the insistence of third-party payers that only claims based on physician prescriptions will be considered for reimbursement.

Moreover, although the American Speech-Language Hearing Association (ASHA) never took such a position officially, some practitioners in the field were long influenced by the dogma that all nonvocal clients (except those whose loss of speech ensued from removal of the larynx for cancer) should learn to speak unassisted and that, accordingly, assistive communication aids were a passing fad. This, too, has tended to discourage coverage of these technologies by third-party payers (51).

There are clear signs that this philosophy is becoming outmoded. The August 1981 issue of the ASHA journal, for instance, was almost wholly devoted to articles that portrayed assistive communication aids in a favorable light. And ASHA had planned to hold a conference on this subject in 1982, but was unable to get the requisite funding from the various Federal agencies to which it applied for support.

Nonetheless, just as medical school curricula neglect this subject matter at both the undergraduate and graduate levels, this has also been true of many speech-language pathology curricula. Again, there are some indications of change. A recent ASHA survey of college and university speech-language pathology programs found that almost 95 percent of them offer at least some course work in augmentative communication and that half of them offer at least one complete course (8). Still, there are practicing speech-language pathologists who got their training before these curriculum changes were introduced and thus are almost entirely unfamiliar with assistive communication technologies. And though familiarization with them may be available in most current speech-language pathology training programs the relevant courses are not always required. Moreover, even if required, these courses may devote only superficial attention to how these technologies are best applied.

In fact, occupational therapists have historically often been more receptive to assistive communication aids than many speech-language pathologists. This lack of receptiveness among speech-language pathologists can have particularly unfortunate consequences for multiply physically disabled children whose lack of speech is congenital. This inability to communicate is often first professionally addressed when they enter school where special education programs more often rely on speech clinicians than on occupational therapists, who, instead, tend to be affiliated with medical centers, or nursing and convalescent facilities.

When speech clinicians who have not been specifically trained to serve this population are, in effect, the providers, it is not only their possible ambivalence towards the technology that weakens its likelihood of reimbursement. It is also that third-party payers are aware that such clinicians may or may not be sufficiently competent to prescribe or to counsel a prescribing physician. Again, this is a disincentive to reimbursement. Administrators of payment programs who have reason to question the competence of the prescriber rarely hesitate to deny requests for funding the prescription, or at least to subject such requests to a process of scrutiny that can delay implementation for months or years.

SUMMARY

In principle, the third-party payment system exists to serve the needs of the handicapped, as well as those of the acutely ill. In reality, it is so fragmented that many of its intended beneficiaries fall into the cracks. A natural tendency to deny or delay reimbursement for assistive communication devices because of their unfamiliarity is intensified by the reluctance or inability of physicians and relevant allied health professionals to make a persuasive case for them. The failure of such professionals to make this case has fueled arbitrary, inflexible, and often inconsistent behavior on the part of third-party payers and deters the dissemination of assistive communication technology and its appropriate utilization.

THE INDUSTRY PERSPECTIVE

Advances in electronics in combination with legislation enacted on behalf of handicapped persons encouraged several firms to enter the assistive communicative aids market by commercializing products developed in research, during the mid to late 1970's. There appeared to be a good fit between the needs of a user population and those of industry. It was, therefore, to be expected that as the companies in question prospered they would plough some profit back into further research and development.

In fact, the expected fit has hardly materialized. The top seller in the field is the Canon Communicator, a portable tape typewriter marketed by Telesensory Systems, Inc., of Palo Alto, Calif.,

which is small enough to be easily carried. Yet Telesensory Systems has been able to sell only about 1,500 of these units since it introduced them in 1977, and its continuing to market them has been at the expense of diminished profits from its other product lines. Meanwhile, the runner-up device—the HandiVoice marketed by Phonic Ear, Inc., in Mill Valley, Calif.—has done only half as well in approximately the same length of time. Although no precise figures are available for the market as a whole, since they are proprietary information, it is evident that sales volumes for the entire industry have been low.

A corollary is that very few of the estimated 75,000 to 1.5 million severely disabled nonvocal persons have had access to these devices, because, at $500 or more each, the devices are beyond most persons' means. An educated guess is that no more than 3,500 to 6,000 nonvocal severely disabled persons have been served by such equipment to date.

The reluctance of third-party payers to reimburse for these technologies is the main reason they are little used. The reluctance has, if anything, grown as public sector programs have had less money to spend and have tended to give expenditures for capital equipment the lowest priority—despite the likelihood that the investment would often permit less client dependency and, therefore, lower taxpayer expense.

In addition, even those applications that have ultimately been approved for funding have often generated lower than expected revenues for manufacturers and distributors because:

1. the firms have had to devote time and effort to helping educators, health care providers, and their clients try to get third-party payers to agree to the purchase;
2. there have often been delays of months to a year or more in reimbursement, and
3. some third-party payers—not only Medicaid agencies—have made it their policy to base reimbursement on only a partial percentage (typically 85 percent) of the listed retail cost of the device.

In many States, these agencies have also made it a condition of reimbursement that the manufacturer or distributor not seek additional money from the person who is to receive the equipment or from his immediate family. At least two firms have therefore stopped doing business with agencies that impose these demands.

Faced with such economic disincentives, private industry involvement in augmentative communication for the severely disabled nonvocal is necessarily restricted. Thus, this industry may well have to put reducing costs ahead of innovation and product betterment if it is to survive at all. The microprocessor and the semiconductor have made state-of-the-art electronic devices for the disabled ready for commercialization. But in the absence of the volume of business anticipated from third-party payments, these technologies are hostages to risk factors that some quarters in industry feel powerless to overcome.

To be sure, this is not always the case. In the fall of 1982, for instance, the Texas Instruments Corp. introduced its Vocaid, which is now being sold to school districts, hospitals, nursing homes, and rehabilitation centers. This is a digitalized artificial voice output communication aid designed primarily for people with temporary or short-term speech loss and sufficient motor control to use its touch-sensitive surface which is divided into 36 squares and comes with a set of overlays that give it a fairly extensive, but not unlimited, repertoire of words and phrases.

However, the device—which sells for about $150—is a spinoff from an earlier Texas Instruments product (the Touch and Tell educational toy for young children). Thus, it might well have never been modified and commercialized had Texas Instruments not already had a running start on this technology.

Similarly, the Apple Computer Corp. has published a resource guide on using computers for the disabled and publicized applications of its products to the communications needs of nonvocal severely physically disabled persons in its magazine (1,18,22). And the Radio Shack Division of the Tandy Corp. has helped to underwrite a contest, sponsored by the National Science Foundation, to make personal computers more accessible and more useful to people with a variety of handicaps.

But neither company has taken steps to go beyond such honest broker roles, apparently because the characteristics of the potential market do not merit industry's direct entry into producing or distributing products specially designed to compensate for communication disabilities.

Meanwhile, those companies that have marketed specialized assistive communication aids have been disadvantaged by the disincentives to third-party payment already discussed. Other discouraging factors from the perspective of industry include the following (36,51):

- High research and development costs for new technical aids or for substantive redesign or modification of existing aids. Such research and development is expensive, because human factor studies are required to adapt equipment operation to the physical limitations of the handicapped, about which little is known to begin with.
- Few nonvocal severely handicapped persons with sufficient education and technical expertise to participate in research and development as professionals and so help industry avoid costly design mistakes.
- Restrictions in some government programs supporting rehabilitation research that make profitmaking firms ineligible for grants and contracts. Some manufacturers complain that this results in developing prototypes in university settings in a manner that fails to take production factors into account, thus making the transfer to commercialization needlessly costly and difficult. However, the Small Business Innovative Research Program that has come into being during the Reagan administration may go a long way towards solving this problem. Already, for example, the National Institutes of Health have awarded grants and contracts, 16 relevant to assistive communications, to small businesses under this program.
- Very high marketing costs associated with reaching the small, diverse, and geographically dispersed population of prospective assistive communication aids users, a problem compounded because speech professionals, special education professionals, physicians, and others involved directly in health care delivery often have little or no knowledge of or training in this field.
- A population of prospective users that is hard to identify because its members are usually classified according to another disabling condition, the manifestations of which sometimes do and sometimes do not include an inability to talk. For example, only a minority of persons with cerebral palsy are totally nonvocal. Similarly, not all those with traumatic head injuries lose their speech either temporarily or permanently.
- A population of prospective users that does not come with a readymade advocacy and service delivery infrastructure built around a shared functional inability to talk. This population contrasts with that of the blind who—despite the fact that they are blind because of a variety of pathologies—have been able to make their common inability to see the central issue in persuading both public and private sectors to help meet their needs. (Of the disabled, note that only the legally blind are automatically entitled to a Federal income tax exemption. Similarly, there is a registry of all agencies and organizations that serve blind people in the United States, but no such registry for those who are unable, for whatever reason, to talk.)

Furthermore, the many groups organized around given diseases or diagnoses (e.g., multiple sclerosis, amyotrophic lateral sclerosis, cerebral palsy, etc.) tend to share very little information about the communication disabilities found in their constituencies and tend not to place issues related to communication at the forefront of their concerns. Perhaps this orientation results from the understandable emphasis of these groups on medical research aimed at the improved therapy, cure, and prevention of the disease in question, rather than on improving the lot of those faced with irreversible impairments resulting from its pathology.

In sum, while advocacy groups are beginning to form around the functional inability to communicate, these groups are still poorly financed and weak. It may be that the same forces that fo-

cused public attention on orphan drugs—drugs needed by too few patients to make their development and manufacture by pharmaceutical firms sufficiently profitable—will eventually come to the rescue of orphan devices for people with serious physical limitations like those with which this case study is concerned (36). But for the time being, at least, these forces have yet to emerge or coalesce.

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